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**CARE STAFF PERCEPTIONS OF ADULTS WITH PROFOUND
LEARNING DISABILITIES: CONTENTS AND PROCESSES**

**A thesis submitted in partial fulfilment of the requirements of the
Open University for the degree of Doctor of Clinical Psychology**

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**SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY COLLEGE**

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Abstract

Background and Aims

This research dissertation attempts to elicit care staff perceptions of clients with profound learning disabilities and the processes involved in these perceptions. There is little research in the area of staff perspectives in this field. Clinical psychologists working in this field often have extensive contact with staff regarding clients, and conflict regarding perception of clients can arise. It is suggested that for psychologists to gain some insight into how staff perceive clients and the processes involved would help to facilitate understanding of, and co-operation, with care staff.

Design and Participants

A qualitative design was employed as the study was seen as exploratory and was investigating the personal experiences and perspectives of participants. Participants were nine direct care staff who worked in a variety of service settings.

Measures

Each respondent completed a written free response description of a client of their choice. This was followed by a semi-structured interview that aimed to explore the processes involved in staff perceptions of clients.

Results

Written descriptions shared some factors in common with free response description within the general population. However, novel categories included communication issues, behavioural difficulties and the disability itself. The interviews suggested that

there were complex processes operating that made it difficult for respondents to acknowledge the disability and still feel positive about the clients and the work. There was also a marked change over time described by respondents in their perceptions of clients.

Implications

It is suggested care staff need a forum for acknowledging and exploring difficult feelings. Clinical psychologists are well placed to facilitate this but must also be aware of their own problems regarding acknowledging and coping with profound disability. Awareness of the issues might also help psychologists to work more sensitively and productively with staff.

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*'I'm fascinated by the other side of human nature,
the feral side, the side that won't answer to our ordinary structures.
Sometimes I see it as a bottomless pit of human need and chaos and I think facts are
facts, that's the story. So it's being in relationship to that, and
I'm involved in a bit of a big question.'* (Respondent)

1. Literature Review

1.1

Introduction

The review of the literature that follows attempts to draw together some disparate strands of research in learning disabilities and in social psychology. Firstly, definitions and implications of profound learning disability will be looked at. The work of Piaget and others in the cognitive developmental field is briefly discussed in order to consider the level of cognitive development the profoundly disabled may be operating at. This is important information to have when considering how accurate and realistic the perceptions of respondents in this study are. The issue of how and if the profoundly disabled communicate is especially considered as this has implications for how others may perceive them.

Following this, there is a brief look at changing attitudes in care provision, especially the possible impact of care philosophies on how clients with learning disabilities are perceived. The historical exclusion and poor treatment of people with learning disabilities

is contrasted with philosophies which emphasise inclusion and seeing the learning disabled as normal. This is important to consider as it may be a factor involved in how care staff perceive the profoundly disabled.

Some mainstream social psychology literature is then considered. The content of person perceptions obtained from the general literature is briefly outlined. This is done in order to provide a comparison with the descriptions of clients provided by respondents in this study. Processes involved in person perception such as impression formation, motivation, and need for relationship are also considered. This is done because it is important to outline processes in ordinary social perception before considering what may be happening in the perception of the profoundly disabled. Also, some processes, such as goals and motivation could have particular relevance for care staff perception of the profoundly disabled.

Relevant research in learning disabilities is then discussed, with an emphasis on the literature on staff/ client relationships. Factors that may impact on how clients are perceived by staff are considered. These include protecting the image of clients, seeing the clients as friends and underplaying the disabilities of clients. The concept of 'personhood' is also explored. The categorisation of 'person' and 'non-person' is socially constructed and has important consequences for how an individual is treated if assigned to the 'non-person' category. Euthanasia is discussed as even life itself can be denied to those deemed 'non-persons', including the profoundly disabled. Therefore, the promotion and preservation of the 'personhood' of profoundly disabled people may play a part in

how care staff come to perceive and describe clients. Finally, the rationale for the study and the qualitative methodology are addressed.

1.2

Profound Learning Disabilities: Definitions

In terms of legislation the category of ‘profound learning disability’ does not exist. The terms used in the mental health legislation (1983) are ‘mental impairment’ and ‘severe mental impairment’. The British Psychological Society (BPS) have published guidelines to explain the definitions used in government Acts (BPS, 1991). Clinically, individual assessment often focuses on individual needs rather than rigid classification. However, sometimes it is the role of the clinical psychologist to proffer an opinion regarding particular classifications. Following publication of the aforementioned BPS document, there was some debate regarding the need for clarification of ‘learning disability’ in relation to ‘mental impairment’.

The BPS document ‘Learning Disability, Operational Definitions’ (1999) gives the criteria for learning disability as significant impairment of intellectual functioning and significant impairment of adaptive/ social functioning, both of these criteria having to be met in the developmental period before adulthood. The assessment of intellectual functioning is carried out via psychometric assessment, an I.Q of 69 or less being the criterion for impairment. Sub classifications are ‘significant impairment of intellectual functioning’ (requiring an I.Q of 55-69) and ‘severe impairment of intellectual functioning’ (requiring an I.Q of less than 55).

Elsewhere, it has been suggested that the I.Q of people with profound learning disabilities lie below 20 (World Health Organisation, 1992). Other definitions have focused on functional aspects of impairment, defining the profoundly disabled as those who, in addition to profound intellectual disability, have no language and are unable to carry out basic self help skills. (Presland, 1982). Many people with profound learning disabilities, because of profound and global brain damage, may have concurrent physical or sensory disabilities, as well as behavioural difficulties, mental health problems or autism (Lacey, 1998).

1.3

Profound Learning Disabilities: Cognitive Processes

It could be argued that the profoundly learning disabled are operating at a very early stage of cognitive development (World Health Organisation, 1992). Piaget (1952) described the sensori-motor stage that typically developing children pass through in the first year of life. During this stage, there is a focus on sensory and motor experiences that gradually develop towards the end of this period into a basic capacity for symbolic thought. Piaget argued that a child in the early sub –stages of the sensori-motor period does not possess the concept of object permanence, that is, they are not able to grasp that an object has an existence independent of themselves.

There have, however, been many critiques of Piaget's model and key reformulations have developed, not least because of ever improving technological methods of enquiry, which have enabled researchers to investigate the abilities of very young infants. For example,

it has been found that very young infants have a concept of object permanence when the emphasis on motor skill to prove this is removed (Bower and Wishart, 1972). Also, children much younger than those Piaget originally described have been shown to have the ability to de-centre, that is, move away from the position of egocentricity and take the perspective of someone else (Donaldson, 1978). However, it must be remembered that all this refers to changing parameters of thought about normal infant development. For the profoundly disabled, extensive brain damage is almost always present from birth and so will affect the emergence and development of all cognitive abilities.

The absence of language development also has considerable implications for the cognitive functioning of the profoundly learning disabled. Kahn (1975) compared children with profound learning disabilities with and without expressive language. He found significant correlations between development of expressive language and the following abilities; visual pursuit and permanence of objects, development of causality, development of imitation and development of means for achieving desired environmental events. Hogg and Sebba (1988) suggest that there is a close link between early cognitive development and the emergence of spoken language, perhaps mediated by the development of symbolic abilities.

However, some writers have been concerned that narrow definitions of language and communication exclude the profoundly disabled from being seen as communicating people. The constrictions of these definitions result in a self-fulfilling prophesy, where nothing the disabled person offers is seen as a communication. In particular, the concept

of intentionality in communication has proved contentious. Kiernan, Reid and Goldbart (1986) argue that ‘communication involves responses made intentionally in order to affect the behaviour of another person’.

Bradley (1998) argues that this insistence on intentionality removes many people with profound and multiple learning disabilities from the ‘communication equation’. He suggests that much research in normal infant development now shows that successful communication can occur where there is no intentionality on the part of one of the participants. This, Bradley argues, is of relevance to people with profound learning disabilities and their carers. Siegal-Causey and Downing (1987) argue that communication can be seen as ‘the successful transmission of a message from one person to another’. This opens up the possibility of motor acts being given communicative significance. This functional approach views communication as being used to control personal experiences and events. It is undoubtedly important as it opens up the possibility of giving the profoundly disabled person what they need and want. However, this definition of communication seems to remove any need for reciprocity, as it depends solely on one person interpreting the meaning of another’s behaviour or motor acts. This requires the interpreter to construe it as a communicative act. The ‘communicator’ does not have to perceive their action as a form of communication or message but it becomes one if the recipient perceives it as such.

Changing Attitudes in Care Provision

The history of attitudes to, and the treatment of, people with learning disabilities in the last and preceding centuries, is a catalogue of misery, encompassing exclusion and neglect (Race, 1995). This went as far as the sanctioning of ‘painless termination’ in the name of genetic healthiness and social necessity by respected members of the medical establishment such as Tredgold (1952). The physical change of de-institutionalisation accompanied by the philosophical and political shift towards seeing people with learning disabilities as having rights and needs, is a relatively recent occurrence (Malin, 1994).

The large scale move out of institutions that occurred in the 1980’s was accompanied by influential philosophies that permeated professional practice, research, service provision and training. The normalisation principle, originally put forward by Nirje (1969) focused on the belief that those with learning disabilities should have ‘an existence as close to the normal as possible.’ The original impetus for this movement in Scandinavia arose from the activities of those concerned with the legal rights of people with learning disabilities. Wolfensberger (1972) elaborated the concept of normalisation into a framework that gave clear direction for those providing services. A great deal of emphasis was placed on the image of people with learning disabilities. This emphasis intensified with the development of the concept of normalisation into social role valorisation (Wolfensberger, 1983a) where the most important consideration was argued to be the creation of valued social roles for those at risk of being devalued in society.

Critics of these approaches have argued that negative consequences can arise from the attempts to help people with learning disabilities lead, and be seen to lead, normal lives. Within a framework of Social Identity Theory (Tajfel, 1981), Szivos and Griffiths (1990) criticise normalisation for being overly concerned with image and competency. They argue that it encourages disabled individuals to try to pass as normal, putting pressure on them to underplay the effects of their disabilities. They also criticise normalisation for failing to recognise the possibility that learning disabled people may derive a positive identity from their position as a disabled person. Brown and Smith (1989) argue that a more political analysis is needed, where, in line with other devalued, minority groups, the learning disabled can have their needs acknowledged whilst being respected for who they are.

In addition to the pressure put on disabled people to focus on their image in order to fit in with 'normal' society, it is also possible that those working with the learning disabled may feel similar pressure to enhance the image of the clients with whom they work. However, this area appears to have not been researched. Areas searched on 'Clin Psych' included learning disability, learning difficulty and mental retardation in various combinations with carers, care staff, care workers and image, abilities, presentation, enhancement, compensation, exaggeration and protection. These searches revealed no relevant research. If care staff wish to present clients in a certain light, this may mean that they have to exaggerate their competencies and underplay their difficulties. It seems likely that in order to do this, staff would need to perceive and believe in at least some of the qualities they were presenting. Consistently presenting what one did not perceive or

believe would be hard to sustain as it would create a good deal of conflict. As will be discussed later, motivation and goals play important roles in the process of social perception.

Hochschild (1983) describes the 'emotional labour' expected of human service workers and argues that finding a balance between a 'working' self and a 'real, authentic self' is a main need of service workers. Too much use of the real self at work can lead to over-involvement. Conversely, too much separation between the real and working selves can lead to alienation.

This view contrasts with that of Rogers (1967) who argues that 'genuineness' and use of the authentic, whole self is a crucial aspect of the helping relationship. What Rogers terms 'congruence' is defined as the ability of a therapist to be themselves totally without façade when with a client, and the therapist is able to fully experience his/her own feelings. Although this is never completely achieved, Rogers argues that the closer the therapist comes to this state, the greater benefit to the client. Within this framework, splitting off the self into 'working' and 'real' components would not be seen as healthy. Rogers however is primarily describing the therapeutic relationship where contact is limited and boundaries fairly narrowly defined. In care work, by contrast, contact is extended and permeates many facets of everyday life. Thus, it could be argued that to constantly strive to bring one's 'whole' self to the work place would be exhausting and not necessarily desirable. For example, Miller (1995) found that amongst HIV care workers, stress and burn out was associated with self-identification with patients,

unremitting involvement in high intensity tasks and intensity of staff/ patient relationships.

Before considering what may happen in the staff perception of clients with profound learning disabilities, it is useful to examine what is involved in social perception within the normal population.

1.5

Perceptions of Others: Content

Zebrowitz (1990) argues that the contents of social perception, that is, what qualities we perceive in others, has not been the focus of much attention in social psychology. The emphasis has been on the processes involved in perception. Methods for investigating social perception categories include linguistic analysis (Heider, 1958), repertory grids (Kelly, 1955) and, most commonly, free response person descriptions (Fiske and Cox, 1979). Categories elicited from this method include physical descriptions, occupation, roles and activities as well as internal, psychological attributes. Subdivisions of this internal attribute category include abilities, aspirations, attitudes and personality traits.

Interestingly, a category that has not arisen from free response descriptions is emotions. Zebrowitz (1990) argues that this is most likely a reflection of the instructions given to participants which seem to elicit more enduring and individuating attributes. However, separate research into emotion perception has shown that people tend to sort emotions into six main categories; love, happiness, surprise, anger, sadness and fear (Shaver,

Shwartz, Kerson and O' Connor, 1987). They found that these basic categories were perceived in others via facial expression, voice, body language and movement. There is some evidence for the cultural universality of the accuracy in judging emotions. It has been shown that posed facial, vocal and bodily expressions are similarly labelled across varied cultures (Rosenthal, Hall, DiMattio, Rogers and Archer, 1979). There are however some cultural differences in the expression and perception of emotions. For example facial expression of negative emotions of Japanese people are harder for others to read (including by the Japanese themselves) than the facial expressions of English or Italian people (Shimoda, Argyle and Bitti, 1978). It has also been shown that females judge the emotional expressions of others more accurately than men, as well as their own emotions being easier to read than those of males (Rosenthal et al 1979, Baron-Cohen, 1996).

The role of perceiver characteristics on person perception has also been researched. Gender has been shown to influence the salience of various traits. Males more often describe others in terms of abilities, whereas females describe others in terms of self- concept (Korten, 1974). Even in the area of concrete behaviours there are differences between men and women. Men describe more non-social activities whereas women describe more interpersonal interactions. This probably reflects the finding that male friendships are characterised by shared activity, female friendships by shared feelings (Caldwell and Peplau, 1982).

Perception of Others: Processes*Impression formation*

When we first meet a person we usually form an impression of them based on very limited information (Zebrowitz, 1990). The physical appearance of a person can create a distinct impression even before any interaction with them takes place. These first impressions may also depend on perceiver characteristics such as mood, stereotypes and cultural background as well as what type of information is being sought. First impressions also influence the inferences that are made about certain traits that we associate with the known qualities. Over time, these first impressions are modified via interaction and exchange of information as relationships develop (Duck, 1986).

Fiske and Neuberg (1990) describe a model of impression formation that involves two processes. This proposes that impressions begin with constructivist processes, where impressions are derived from pre-existing concepts and theories about particular categories of people and move to structuralist processes, where impressions derive from the target's actual attributes. They argue that constructivist processes are most common, with structuralist processes coming more into play when the target is personally interesting or relevant to a perceiver, and the perceiver is unable to fit the target's attributes to an initial categorisation. Fiske and Neuberg (1990) point out that where information about the target remains limited or is ambiguous the characteristics and

values of the perceiver can play a large part in how a person is perceived. It could be argued that this is very pertinent to considering how people with profound learning disabilities are perceived. However, even without ambiguity, the role of values and goals in social perception is a very crucial one.

Motivation and Perception

The importance of motivation in social perception has had a fluctuating importance attributed to it in the field of social psychology over the years. It seems unlikely that we perceive others in a vacuum, and there is some evidence that we perceive in others qualities that we need or wish to find. Snyder (1998) makes the point that motivation is about how people move through their lives, making sense of the world via social contexts and other people in their social networks. Snyder argues that personality and social psychology are fundamentally motivational in their orientation. The idea that people engage in cognitive activity in order to gain stable and predictable images of the world, an idea that underlies much of attributional and cognitive theory in social psychology, is fundamentally a motivational idea. This, Snyder argues, places the activities of social perception and social interaction firmly in a goal directed context.

Goals and values can operate at a number of different levels in influencing social perception. Hilton (1998) describes the difference between explicit goals, non-conscious goals and implicit goals. Explicit goals are those that a perceiver could articulate, if asked. There is now considerable evidence that these explicit goals affect perception. For example, Wyer and Gordon (1982) found that when people are instructed to form an

impression, they remember more of the target's behaviour than when they are told to simply remember the behaviour.

Non-conscious goals on the other hand are much less consciously carried out in the process of perception. Stereotyping is a good example of an automatic, non-conscious process that takes place in social perception. For example, Devine (1989) found that both high and low prejudiced groups often have the same initial reaction when encountering members of a stereotyped group. However, the low prejudiced people engage in subsequent conscious controlled thinking and reject their original reactions. Finally, implicit goals, Hilton argues, are the backdrop against which social interaction takes place. These are not usually available to the perceiver for examination and would include complex social and cultural values that have become embedded in the person's self-concept and their view of others.

The activation of goals and values in social perception also implies that the position of the target (the person being perceived) in relation to the perceiver is also crucial. We see oneself and others as belonging to a variety of social groups. These groups can be arranged around factors such as age, race, gender and occupation as well as around beliefs and values. The in-group favouritism hypothesis (Tajfel, 1970) postulates that we see more positive qualities in the behaviour of people in our own group than the behaviour of those in other groups of which we don't feel ourselves to be a member.

Attribution

Attribution is the process via which causes are looked for in a person's behaviour by a perceiver. One of the main findings in this area is actor-observer difference in causal attributions. Jones and Nisbett (1972) argue that observers tend to attribute the target person's behaviour to internal causes as their attention is focused on the target with the situation as background. In contrast, people tend to attribute their own behaviour to external causes because they are focusing attention on their environment and the people within it. However, this difference can be reversed when attentional focus is manipulated so that actors and observers can see interactions from the other's perspective (Storms, 1973). Also, observers are less likely to attribute behaviour to internal attributes when they are attempting to control the actor's behaviour (Swann, Pelham and Roberts, 1987). Also of interest is the fact that under some circumstances people overestimate the role of situational factors and underestimate the internal factors in someone's behaviour. For example, Quattrone (1982) found that when perceivers were sensitised to the possibility of environmental constraints on a person's behaviour, they saw these environmental factors as causing the behaviour even when the behaviour was totally explicable in terms of the actor's stated attitude.

These findings offer an interesting perspective on how normalisation and social role valorisation could impact on care staff perception of clients. These movements heavily emphasised the environmental constraints that had been placed on people with learning

disabilities and focused on changing environments in order to promote positive changes in quality of life. Referring directly to the impact of a person's disability on their abilities, behaviour and emotions was discouraged.

Need for Relationship

Weiss (1998) talks of a human need for inclusion and acceptance and a need to experience life as part of a community or network of others, however small. Although this is a universal need, it has been found that people differ in their need for affiliation (Brock, Sarason, Sanghvi, and Gurung, 1998).

As Duck (1999) points out there are many types of relationship, each with differing types and levels of intimacy; parent / child, employee / employer, lovers, colleagues, amongst others. These all take place against a cultural backdrop and there are enormous cultural variations in how relationships are carried out and expressed. It has been shown that we prefer people who are similar to ourselves (Duck, 1994) and we also get to like people more if we have a lot of contact with them.

It could be argued that these findings on relationship development suggest problematic issues for staff working with the profoundly disabled. People's need for affiliation and tendency to like people they spend a lot of time with, suggest that care staff may be drawn to like clients and build relationships with them. Conversely, if we like those who are similar to us, it may be difficult to build relationships with people who are so very different. The issue of relationship type also seems problematic. Clients and staff are not

a parent and child dyad, or colleagues, or friends, yet often have a great deal of close contact. Therefore, where staff position themselves in relation to clients may be problematic. Of course, one could define the relationship as carer/ cared for, similar to many other care type relationships, but this may itself be problematic for a number of reasons. The drive towards equality and normality fuelled by normalisation/ social role valorisation may make the power differentials inherent in this relationship uncomfortable for care staff, especially as the level of care required with this client group is so all encompassing.

1.7

Relevant Research in Learning Disabilities

There is little research that looks at social perception and interaction involving people with learning disabilities, particularly those with more severe and profound learning disabilities. Some research has focused on staff/client interactions and much of this focuses on challenging behaviour and the role of staff behaviour and attitudes (e.g, Dagnan, Trower and Smith, 1998, Hastings and Remington, 1994).

Clegg (1994) argues that different conceptualisations of staff/client interactions are needed. She argues in favour of research that uses more reflexive methods. Clegg (1993) also argues for a social constructionist approach to learning disability. This approach locates the learning disabled in a social context, thereby allowing clinical psychologists and other professionals to address a wider range of client difficulties. Clegg (1993) stresses the interpersonal level as the most relevant focus for clinical research and for

clinical practice, and argues for the importance of combining work with a referred individual with intervention in their social environment. This implies, she argues, long term involvement supporting teams of staff rather than short- term interventions with individuals.

Clegg (1993) also stresses the need for a collaborative approach between professionals and care staff, focusing on the sharing of difficulties as opposed to professionals giving instructions to be carried out. The social constructionist view of learning disabilities also implies that a systemic view could provide a useful framework within which to view both client and staff problems. Although this approach has been used with families where there is a learning disabled member (Dixon and Matthews, 1992; Goldberg, Magrill, Hale, Damaskinidou, Paul and Tham, 1995), it has not really been extended to looking at clients in staffed environments. Therefore, it is difficult to evaluate how useful or applicable this approach may be in staffed settings.

A review of the literature that looks at staff/client interaction (Clegg, Standen and Cromby, 1991) shows that social contact is rarely mutual. Staff tend to approach clients in one way care. Clegg and Standen (1993) found that many staff working with the profoundly disabled lacked confidence that interactions with clients were purposeful. Although staff may have doubts about their interactions with clients, it is also possible that staff may try to overlook the severity of disabilities in an attempt to feel closer to the client. For example, Bartlett and Bunning (1997) found that care staff consistently overestimate the communicative abilities of clients with learning disabilities, with staff

using language that was beyond the measured comprehension level of clients. Jenkins, Rose and Lovell (1997) found that some care staff tried to deny access to professionals in order to 'protect' the images of clients with challenging behaviour. Brown (1997) found that some staff saw themselves as friends to the clients, particularly if the client seems lonely and has little life outside the care environment.

Therefore, it seems likely that care staff perceptions of clients could be influenced by how staff interpret clients' needs. The personal need of care staff for meaningful interaction could also influence their perceptions of clients. This may be even more likely for clients with profound learning disabilities where communication is much more problematic and staff play a larger role in their social and emotional lives. From a psychodynamic perspective, Sinason (1990) suggests that care staff can feel considerable distress about the disabilities of the clients they work with and guilt that they are not themselves disabled. In an attempt to deal with this, she argues, staff can try to underplay the disabilities and attempt to promote the 'normality' of clients. This guilt and distress may not be conscious but could possibly interact with the more conscious efforts fuelled by the normalisation and social role valorisation philosophies. There is little evidence for this perspective and few authors address the role of such difficult emotions in how disabled people are perceived, especially learning disabled people. Thomas (1997) however, looks at the role of countertransference in therapy with physically disabled people. He highlights problematic psychodynamic factors that can arise in the therapist. These include fear of loss of love, fear of death, anxiety regarding self disintegration and ego defence mechanisms such as projection and denial.

Personhood

There are clearly potential difficulties in trying to make sense of people with profound learning disabilities within our cultural constructs of what it means to be a person. King (1997) found that parents puzzled over the personhood of their adult learning disabled offspring. Key problematic features were the unknown inner life of the learning disabled person, the personal agency or will of the individual, lack of consistency in actions and responses, and the mixture of child and adult behaviours and characteristics.

The concept of personhood has not been very well defined and, apart from the above mentioned study, does not appear in the literature in relation to people with learning disabilities. It does, however, appear in relation to other devalued groups. For example, Harrison (1994) argues that those suffering from dementia have their personhood threatened due to the huge changes and losses that occur across all domains of the person. Harrison argues that appreciating the integrity of the individual's life by looking at the illness within the context of the whole life may help to preserve their personhood. Immediately one can see the problems this approach may cause for those attempting to establish or preserve the personhood of the profoundly disabled. There is no 'non disabled' part of the life, past or present, within which to locate the profound disability. The integrity of the life and the person has to be achieved within the context of that person as always profoundly disabled.

Sanders (1995) explores the 'death encounter' of euthanasia. He argues that personhood is a matter of social definition and has certain consequences. Those excluded from the category can be routinely disposed of. By contrast, the deaths of those defined as autonomous and self-aware, with whom an emotionally rewarding relationship can be shared, cause intense grief. Sanders (1995) suggests that the issue of constructing social identity is most strikingly revealed by examining interactions with those defined as bordering between identities of person and non person. These include foetuses and the terminally ill or comatose. In this context, it can be seen how powerful is the need to see the profoundly disabled as having personhood, when the consequences of not doing so are considered. As was discussed earlier, historically there have been calls for the severely disabled to be exterminated, showing perhaps how important the need is to confer the socially constructed concept of personhood on them as a protection against these attitudes and actions.

Looking at staff/ client relationships in more depth, Clegg, Standen and Jones (1996) attempted a qualitative analysis of how care staff saw their relationships with clients with profound learning disabilities. They describe different types of relationship; '*provider*', a one way effort where basic care needs are met but no sense of social relationship exists; '*meaning- maker*' where staff go to great lengths to make sense of moods and behaviour; '*mutual*' where staff describe shared feelings and there is an emotional quality to the shared experiences; finally, '*companion*' which Clegg describes as existential, involving quiet shared time, a lot of touch and a sense of trust and ease without demands or stimulation.

Clegg et al (1996) also discusses staff relationships with external professionals. They found that staff sometimes saw professionals as a source of support, introducing new ideas and approaches. However, sometimes staff found the input of external professionals stressful and complicating, particularly where staff are asked to carry out procedures the client objects to or finds distressing. This obviously has implications for clinical psychologists attempting to work with staff.

1.8

Rationale for study and methodology

Care staff perceptions of adults with profound learning disabilities have been little investigated. Although types of relationships between care staff and clients have been described (Clegg et al, 1996), how these relationships develop and what care staff base their understanding of the clients on has not been looked at. In the light of potential staff conflict with professionals it would be useful for such professionals, especially clinical psychologists, who often work with staff, to have a greater understanding of how care staff see the clients and the processes that underpin their views.

Qualitative research methods offer rich scope for investigating and making sense of personal experiences and are particularly suited to uncovering what lies behind phenomena about which little is yet known (Strauss and Corbin, 1990). Areas of study that attempt to uncover the nature of personal experience in a particular setting also lend themselves more to qualitative investigation.

Interpretative phenomenological analysis (IPA) as described by Smith (1996) attempts to explore in detail the participant's view of a topic. It focuses on the individual's perception of an account or event as opposed to attempting to produce an objective account. IPA attempts to understand what the participant thinks or believes about the topic under discussion. This study attempts to focus on the personal experiences of those who have worked with the profoundly disabled and examine their accounts of the clients they work with.

A grounded theory methodology (Strauss and Corbin, 1990) was also considered for this enquiry as it seeks to discover from the data, building theory from collection and analysis of data. It is a method from which IPA developed. This approach does not begin with a pre-existing theory but with an area of study, allowing what is relevant to emerge. However, grounded theory is a more appropriate methodology where there are larger samples than the one used here. IPA also claims less in terms of developing a model.

Discourse analysis as described by Potter and Weatherell (1995) was considered as an alternative methodology as the language used by care staff to describe clients was seen as a key feature of the research. Also, as Potter and Weatherell argue, typical topics for discourse analysis research are often social psychological or sociological. The goals of such research are to contribute to our understanding of issues such as identity, constructions of self and others as well as the conceptualisation of social interaction. However, as Smith, Jarman and Osborn (1999) point out, discourse analysis does not

attempt to match verbal reports with underlying cognitions, being more concerned to draw out the interactive tasks being performed by verbal statements. IPA in contrast is very much concerned with cognitions, that is, what a respondent believes about the interview topic. There is an attempt to get beneath the verbal statements, whilst realising that it will never be an objective, literal representation of a person's thoughts, beliefs and feelings. To attempt to say something about the factors that lie behind the respondents' descriptions of clients is an aim of this research. Therefore, IPA seemed more appropriate to this endeavour although it is recognised that there may be overtones of discourse analysis involved. For example, attention will be given to how respondents position the clients in their social world and how respondents position themselves in relation to the perceived views of others.

1.9

Research Questions

1. How do care staff perceive and describe clients with profound learning disabilities?
What are the main features of these descriptions?
2. What are the processes involved in care staff arriving at their perceptions of clients?
3. How do care staff think the general public, clients' families and outside professionals perceive clients?

2. Method

2.1

Design

A qualitative design was chosen for this study. A collective case approach was used (Stake, 1994). This involves selecting a number of cases with the aim of achieving a better understanding about a still larger collection of cases. The cases are selected because of a common experience but may or may not manifest common characteristics.

2.2

Sampling and Recruitment

Purposive sampling (Morse, 1994) was used to obtain participants. In contrast to random sampling, this focuses on accessing participants who are potentially a rich source of data for the areas being investigated. Prospective participants were approached via the process of networking and snowballing. (Patton, 1990). People known to the investigator who had experience in the field of profound learning disabilities were asked to distribute an information sheet to people known to them who may be interested (see appendix 1). This also included a consent form. Prospective participants were not approached through places of employment. The aim was to recruit people with varied experience within the parameters of the research, not recruit from one or two settings, where a 'group' view rather than an individual one may have been elicited.

The criterion for participation was at least one year's experience in direct care work with adults with profound learning disabilities. Profound learning disabilities was defined as 'people with little or no verbal communication who need considerable help in all activities of daily living' (Presland, 1982). It was accepted that the clients whom participants chose to talk about may also have physical or sensory disabilities, behavioural difficulties or autism in addition to profound learning disabilities, as profound learning disability is often accompanied by these other factors (Lacey, 1998). All people who returned the information sheet with a signed consent form were then contacted.

2.3

Participant Details

Thirty-five information sheets were distributed in total. Eleven people returned the consent forms and nine of these took part in the interview process.

There were nine participants, five women and four men. Their ages ranged from 26 to 51. Two respondents worked in the same service setting. All other respondents were from different service settings to each other. Their experience in care work in learning disabilities ranged from two years to nineteen years. The full respondent details are as follows (table 1):

Table 1: Participant Details

Freddy	Age, 37 : Day care worker, severe and profound learning disabilities. 14 years experience, residential and day care work, severe and profound learning disabilities.
Gina	Age, 51 : Day centre officer, severe and profound learning disabilities. 10 years experience, day care and residential work.
Andrew	Age, 33 : Residential worker, severe and profound learning disabilities. 2 and a half years experience, all residential.
Kerry	Age, 30 : Residential worker, mild learning disabilities and mental health. Relief worker, residential, severe and profound learning disabilities. 12 years experience, residential and day care, all levels of learning disability.
Tracy	Age, 33 : Day centre worker, profound learning disabilities and challenging behaviour. 7 years experience, residential and day care, mainly severe and profound learning disabilities.
Annette	Age, 32 , currently social worker, left care work 3 years ago, 7 years experience, 4 years residential, profound learning disabilities and 3 years with mild learning disabilities.
Shelley	Age, 26 , not working since last year, on maternity leave. 7 years experience, mainly residential. 5 years with profound learning disabilities, 2 years with mild learning disabilities.
Steve	Age, 33 , day centre officer, 8 years experience, profound learning disabilities
Alf	Age, 47 , day centre officer, profound learning disabilities. 19 years experience, residential and day care, all levels of learning disability

2.4

The Interview Schedule

A semi-structured interview schedule was constructed (see appendix 2). As described by Smith (1995), the semi-structured as opposed to the structured interview format follows from the phenomenological position. The investigator has an idea of the area of interest and some questions to pursue. However, the investigator also attempts to access the psychological and social world of the respondent. Therefore, the respondent can shape the direction of the interview and introduce issues the investigator had not thought of.

This interview schedule was constructed to address the main research questions and included areas of interest to be covered. A description of a particular client was asked for in order to compare to ordinary free response descriptions. Also, it was envisaged that asking respondents to talk about a particular client would elicit better information about the processes involved in perception than asking them to generalise straight away.

Some question areas consisted of direct asking of a research question, for example, asking how other groups (public, families and professionals) see the clients. Other question areas were based around existing literature, for example, how perceptions change over time relates to the literature on impression formation. Asking about motivations and expectations is based on the literature on the role of motivation and goals on perception (Snyder, 1998). The aim was to explore how these areas manifested in staff perception of this client group.

The interview schedule was discussed with two clinical psychologists in learning disabilities, who gave advice regarding wording and structure. The interview was piloted on one person. As this went well and led to no changes being made, this interview was included in the final data analysis.

In the interviews respondents were encouraged to talk about the question areas freely but prompts were included in order to gain information about the areas under investigation.

2.5

Procedure

On receipt of completed consent forms, prospective participants were telephoned in order to arrange interviews. At this time, they were also encouraged to ask questions about the research and the procedure. As participants were being asked to talk about clients, the importance of client confidentiality was raised from the beginning by the investigator. Most of the participants were also keen to discuss this, and the investigator stressed the importance of withholding identifying details. Participants were made aware both on the information sheet, and verbally, that interviews would be confidential. However, they were informed that the research supervisors and examiners would read the interview transcripts. They were also informed that they could withdraw at any time and that nothing which could identify them or any clients they talked about would be included in the write up of the research.

Interviews

Seven of the interviews were conducted in participant's homes. For reasons of personal safety, a contact number and the time interviews were due to finish were left with a contact person. Two participants wanted to be interviewed at their places of work during their lunch break. They obtained permission from their managers to do this. Before commencing interviews, participants were asked if there was anything they wished to clarify or discuss. The importance of client confidentiality was once again pointed out.

Participants were then asked to write a brief description of a client they had worked with (see interview schedule, appendix 2, for instructions). Instructions for this exercise were given verbally and respondents could ask questions about the instructions and clarify any uncertainties before proceeding. Following this they were interviewed using the semi-structured interview schedule (appendix 2) and this interview was taped. In order to avoid participants feeling that they were being interrogated about what they had written, they kept hold of the written piece and discussed it, rather than the investigator taking charge of it. The interview began by participants being asked to talk about what they had written and describe how they had come to know these things about the client. The interview broadened to investigate further facets of how respondents came to know the client and the processes involved in this, including communication and relationship development. The interview also focused on the respondents' interpretation of the perceptions of others involved with the clients. This broadened into considering general experience with client group, moving away from focusing on one client.

At the end of the interview, participants were asked how they felt about the interview process and content. They were also told that they could further contact the investigator if there was anything that had arisen from the interview that they wished to discuss. All participants appeared to respond positively to the interview, describing it as interesting and thought provoking.

For one respondent there was a longer debriefing session as she had discussed being unhappy at her place of work. She did not appear upset by the interview and seemed to appreciate expressing her feelings. However, it was important to check that she had somewhere to take these feelings and reinforce the fact that she could make further contact if she wished. She also made it clear that the negative practices she was concerned about had been raised at higher management level and were being discussed.

2.6

Ethical Issues and confidentiality

As the study involved a non-clinical population, ethical approval was sought and gained from the Salomon's Ethics Panel (appendix 3). As the consent of clients was not possible and was not sought, particular thought had to be given to ensuring that the anonymity of clients was protected. The steps outlined below ensured that only the respondents knew the identity of clients they were discussing.

Participant confidentiality was ensured via the use of pseudonyms on transcripts on computer and on printed transcripts. All audio- tapes, discs and printed data were kept in

a secure filing cabinet. Client confidentiality was ensured via several reminders to participants not to use any identifying details in their descriptions and discussions. Although participants were asked to use a pseudonym for clients if they wished to use a name, to further ensure confidentiality, no names were typed on transcripts. If a name for a client appeared on the tape it was transcribed as an 'X'. Further, any potentially identifying features such as locations were transcribed as a black line.

2.7

Data Analysis

The interviews

All interviews were transcribed verbatim. Using IPA as described by Smith, Jarman and Osborn (1999), the interview transcripts were analysed using an ideographic, case study approach. Smith et al (1999) argue that this approach works well with a small sample size of up to ten participants, as one can retain a picture of each individual case and themes within them. This is illustrated in the present study in the results section, where quotations aim to show how the various themes, although common to respondents, manifest in subtly different ways between respondents.

Following the ideographic approach, each transcript was read a number of times, with anything of interest being noted in the left- hand margin. As connections began to form between ideas, emerging theme titles were noted in the other margin. Connections were then looked for between the emerging themes, seeing which of them appeared to cluster together in order to arrive at a list of master themes. As each transcript is examined new

themes may emerge or ideas which give a different angle on themes already noted. One then returns to earlier transcripts in order to re-examine them in the light of this new understanding. The research diary (appendix 4) shows examples of this process.

When all the transcripts had been examined in the above way, a consolidated list of super-ordinate themes was drawn up. As Smith et al (1999) point out, the analysis has to be selective as not every theme can be given prominence. Also, prevalence of theme illustrations are not the only criterion for selection. A particular passage may be very rich and illuminating and help illustrate other aspects of the account. This was particularly true for the present study where particular passages gave a sense of where certain ideas and conflicts may be coming from. Also, powerful themes emerged that seemed to link the interviews and these were focused on. Obviously, if one is looking for commonalties, there will be a tendency to find them. However, this does not preclude the investigator from being aware of differences. In the present study, one respondent did stand out as different and this will be discussed in due course. Also, as noted above there is an attempt to illustrate the different accounts via use of quotations in the 'results' section.

As an example of the data analysis process for one respondent, appendix 5 shows sub-themes, with quotes, from one transcript and how they group together meaningfully to produce the main themes. Appendix 6 is the entire transcript for this participant.

The written accounts

The hand-written descriptions were typed up verbatim. The written accounts were analysed using content analysis. Manifest content analysis involves searching a document for particular contents and categories which are established prior to the analysis (Krippendorff, 1980). In this case the categories established were those relating to free response person descriptions as described by Fiske and Cox (1979). New categories were also created if the written material did not fit any of the existing categories. The purpose was to extract the main content areas. (See appendix 7 for an example description with coding).

2.8

Reliability and Validity

Ninety quotations were taken from the transcripts and given to an independent rater, a clinical psychologist who was not involved with this research. The rater was given a list of definitions for each theme (see appendix 8). The resulting judgements regarding to which theme each quote belonged was compared with the investigator's ratings of the same quotes. Cohen's Kappa coefficient was calculated which resulted in a value of 0.80 (see appendix 9 for details).

Three of the written descriptions were also given to a separate independent rater, with a description of categories (see Appendix 10). These descriptions had parts of the text underlined, with each underlined chunk numbered (as in appendix 7). There were 31 underlined bits of text altogether. For each underlined bit of text, the rater allocated a

category from the list. These were compared with the investigator's allocation of categories. Again, Cohen's Kappa coefficient was calculated which resulted in a value of 0.93 (see appendix 11 for details).

Internal validity is demonstrated by ensuring that the investigator presents the reality of participants through a coherent story line and excerpts from their interviews (Holloway, 1997). Schofield (1993) suggests a coherent description of the situation under study, consistent with the evidence that supports it, including a description of the decision trail and demonstrating evidence for statements that are made.

External validity refers to the generalisability of the research, which is often difficult to establish in qualitative research if the area under study is very specific to a particular location. In this study, an attempt was made to recruit participants from a variety of locations. However, there were still limitations regarding generalisability, and these are addressed in the discussion section of this report.

2.9

Feedback to Participants

A brief presentation of the results was sent to participants (appendix 12). It was kept fairly simple because the results indicated that some themes might have been potentially difficult and conflictual for participants. However, all respondents had been very keen to see the results and it did not seem appropriate to withhold them. On receipt of the results, respondents were encouraged to make contact if there was anything they wished to discuss.

3. Results

3.1

The Written Descriptions

The written descriptions varied in length from a few lines to a whole page of A4 paper. The categories obtained from the content analysis are shown in table 2. (All pseudonyms used are for respondents, not clients).

Table 2: Categories obtained from free response written descriptions.

Category	Descriptions including each Category	Sample quotes
Communication	Gina, Andrew, Kerry, Tracy, Shelley, Steve, Alf.	'Communication seems contradictory. A major difficulty is in establishing a yes/ no response'. (Andrew)
The disability	Freddy, Kerry, Tracy, Annette Steve, Alf.	'A man in his mid thirties with profound learning and physical disabilities.' (Freddy).
Personality traits	Freddy, Andrew, Kerry, Annette, Shelley	'this person had a great sense of humour'. (Shelley).
Emotions	Freddy, Gina, Kerry, Shelley, , Steve, Alf	'He can show happiness, annoyance and dislike.' (Steve).
Likes/ dislikes	Freddy, Gina, Andrew, Kerry, Tracy, Shelley	'He's a great lover of music' (Andrew).
Abilities (can do)	Freddy, Gina, Andrew, Tracy Shelley, Steve, Alf	' He has perfect balance, on one chair leg, for example'. (Gina)
Aspirations (wants)	Freddy, Gina	'very determined to walk and run whenever he is given the opportunity,. (Freddy)
Positive label	Annette, Shelley, Steve	'a fantastic guy to work with' (Shelley)
Negative label	Tracy, Alf	'he is the most difficult client in the centre to work with' (Alf)
Activities (what the person does)	Gina, Andrew, Kerry, Tracy Annette, Shelley	'he spends most of the night and day in bed' (Tracy)
Difficult behaviour	Gina, Andrew, Tracy, Shelley, Alf	'He can be violent towards objects or other people, and himself' (Tracy).
Physical Appearance	Tracy, Shelley	'X is a man of slight build'. (Tracy)
Shared Activities	Freddy, Annette	'We spent time together walking and attending gigs.' (Annette)
Social Role	Freddy, Steve	'Very much valued as a son, brother and uncle'. (Freddy)

Many of the categories were similar to those found in general free response descriptions, namely, personality traits, activities, shared activities, social role, wants, likes and dislikes, physical appearance and abilities. Some details, though, were quite different from what one would expect from a general free response description. For example, in activities, there is no mention of formal occupation and 'abilities' often refers to simple motor acts or communication.

Categories elicited from this analysis that are not generally found in free response descriptions were; the disability, communication, difficult behaviour, positive and negative labelling, and emotions.

Some descriptions, for example, those of Shelley's and Freddy, combine many of the categories. Others, for example, those of Steve and Alf focus heavily on the disability and communication issues in their descriptions.

3.2

The Interviews

The interviews focused firstly on attempting to find out how people got to know the various things about the client that appeared in the written descriptions. This tended to elicit a quite straightforward and easily describable process that involved care staff observation of clients.

As the interviews developed, more complex themes emerged that suggested influences on how the respondents perceived the clients. There appeared to be two meta-themes which provide a framework within which to locate the themes. Firstly, conflicting perceptions and descriptions of clients within individual interviews. During the analysis many themes appeared as dichotomies and are expressed in this way below. Some respondents seemed aware of the dichotomies at times. However, often dichotomies became apparent when comparing statements from disparate parts of interviews. Secondly, there is a strong sense of change over time in respondents' perceptions of clients.

The themes also cut across research questions two and three, that is, what processes are involved in care staff perceptions of clients and how they think other people perceive the clients. For this reason, the research questions will not be divided in presentation of results. The text will indicate how the themes that arise relate to the research questions.

The following table shows the main themes elicited from the interviews and the respondents that supported each theme. The text that follows the table elaborates on the themes, showing the variety of ways they manifested.

Table 3: Main interview themes.

Name of Theme	Respondents
Observation of clients	All respondents
Knowing <i>versus</i> uncertainty	All respondents
Client as ‘normal’ <i>versus</i> ‘not normal’	Freddy, Gina, Andrew, Kerry Annette, Shelley, Steve, Alf
Emotional Connection <i>versus</i> detachment	Freddy, Gina, Andrew, Kerry, Shelley, Steve, Alf
Client as a person <i>versus</i> not a person or part of the person	All respondents
Negative perception of clients <i>versus</i> positive	All respondents
Client as child <i>versus</i> client as adult	Freddy, Gina, Kerry, Tracy, Annette, Shelley, Steve
Locating self with client	Steve, Freddy, Gina, Tracy, Annette, Shelley, Alf,
Influence of colleagues, teams and care philosophies	Freddy, Andrew, Kerry, Tracy, Annette, Shelley, Steve

Observation of Clients

All respondents gave numerous examples of how they made sense of the clients’ wants, needs, likes, emotions and personalities. This process was based on observation of the following phenomena:

Table 4: Types of observation involved in perception

Observed phenomena	Examples
Facial Expressions	‘If he liked someone, he would give a look of pleasure to see you. He’d tilt his head and give a fantastically sunny smile’(Shelley).
Body Language	‘when he likes something his body language becomes more relaxed’ (Gina)
Noises and Vocalisations	...’...producing a lot of excitable noises and sounds when enjoying himself which would be markedly different from agitated sorts of sounds’ (Andrew).
Other Behaviour	‘he gets agitated and starts biting’. (Alf)

For all the respondents, the descriptions of how they came to understand a client in these ways showed what an all consuming and arduous task it is, and yet still leaves a sense that all that effort can in no way match the experience of verbal communication. For most respondents this was implicit in the interviews rather than being directly expressed as a point. Shelley however, put it very directly;

‘We use talking amongst ourselves and not to be able to talk to someone and them talk back to you, I find it very, very hard.....I think you become mini experts at reading people's body language and how their face is and what noises they're making, what tone and what pitch and you just become so tuned to their body and what they're doing with their body, even though you can't get over the fact they can't talk.’

Knowing versus Uncertainty

Expanding on the previous theme, this is about the importance of knowing the client in order to understand them but at the same time, the difficulty of knowing and having to work with uncertainty. This theme seemed to arise particularly as part of the process of respondents talking about their written descriptions, explaining how they came to know things about the client. Within individual interviews there were examples of the respondent at times feeling they know and understand the client and at other times not knowing. For example, Andrew;

‘...you do need to know the client for a while to understand what he’s trying to get across...’

and later;

‘...you will get those unaccountable outbursts and moodswings and they are unaccountable and will probably remain so’

For some respondents dealing with this uncertainty was a particularly difficult aspect of the job. For example, Alf;

‘No, I don’t know what’s going on, and that’s the most frustrating part of the job really. Because we’ve got people with all sorts of learning disabilities, some of them you know what’s going on, you can actually verbally communicate or eye contact.....and you can see what they want or they

know what they want and you can tell this. But you don't know all the time, sometimes it's impossible.'

The importance of knowing was also discussed in relation to having historical information about the client, passed on by others who have had more or longer contact with the client. For example, Steve;

'One client vocalises like an ----- and you would never understand what it was about unless you spoke to the relatives that told you he used to like watching ----- films.'

Although the focus of this dichotomy was often around the practical difficulty of making sense of behaviours, facial expressions, noises and body language on a day to day level, for some respondents there was also speculation about what could never be known. For example, Annette;

'I'd really like to know what he was thinking. I mean, the human mind is such an amazing tool, it can't just be not doing anything. Whilst he is perceived as not doing anything because he's not reacting in some way, I'd like to know what's going on inside his brain or what he's thinking about me.'

Freddy continues with speculating about what is unknown and can't be known and juxtaposes this with accepting the person for what is apparent. He makes clear just how

difficult this ‘juggling’ process can be. This is a long quote but is important as it shows clearly how cultivating a view of the person as more able can be seen as a protective device against negative emotional reactions to the disability, another theme which emerges and will be discussed later. It also shows the role of fantasy which can operate when there are perceived ‘gaps’ in knowledge about the person to be filled.

‘I’ve no idea what his real feelings are toward particular people. It’s frustrating not being able to know, you feel you’re only scratching the surface really.....I mean, you can imagine or hope for maybe a lot more but sometimes that’s maybe not the right way to think about people because you’re not accepting people for how they are. You’re kind of wanting to fill in the gaps. I used to have dreams where he was talking, it’s a need that people have to fill in the gaps.....it’s not necessarily a bad thing but sometimes maybe you’re trying to compensate for that person’s disabilities and subconsciously not accepting, finding it difficult to accept how difficult that person’s life can be and how vulnerable a person is.’

Other respondents give a suggestion of what this filling in of the gaps may look like. This is can take the form of speculating about what has been lost or what might have been there but for the disability. For example, Kerry;

‘I always said that if he didn’t have a learning disability I could just imagine he’d be the sort, a big, crappy escort van and lots of tattoos and clubbing

every week and drinking beer. That's how he seemed. That's the kind of guy he would have been.'

Annette also suggests this quality of 'would have been' but seems to struggle with where to locate the quality she is talking about, in the person as they are or in the person as they would have been:

'You know, I could imagine he would be quite a charmer, as a person, you know, he is to me.....he's quite a charming person and I can imagine that he would be quite a -- well, he is.' (author's emphases).

The contrast between knowing and not knowing was also apparent when respondents talked of outside professionals' views of the clients. Here, the contrast is between the respondents who know and the outside professionals who don't. For example, Gina;

'I know one social worker who found him to be a complete mystery but she didn't actually have the opportunity to get to know him.....he was completely unknown to them.'

Client like normal people versus different from normal

This theme manifests as respondents at times emphasising the difference of clients and at other times stressing the similarities to the non-disabled population. This perception of either normality or difference came up in relation to various issues, for example, behaviour, appearance, relationships and abilities. This dichotomy was occasionally expressed consciously as by Freddy:

‘.....sometimes you’re trying so hard to treat someone as you would anyone else but then you have to pull back because that person has a learning disability’.

However, more frequently this dichotomy was expressed in a more disjointed way with respondents focusing on differences from the normal population in some parts of the interview and similarities to normal in other parts. For some respondents this was most obvious when describing the change in their views over time. Initially negative feelings are there on first meeting clients or before meeting them. Over time these feelings change to acceptance and a focus on seeing the client as normal. However, the conflicting views remain. For example, Shelley;

‘They frightened me, they frightened me because I hadn’t ever met a person like that before..... I thought ‘oh my god, they’re not like normal people’.

And later;

‘.....he just came across to me like a typical lad, just very up for it, a bit wild’

And;

‘And I don’t think we can say they are exactly like everyone else but then no-one’s the same’

For some respondents, the emphasis on normal moved further into suggesting the clients may be superior to normal in a variety of ways. Again, at other stages of the interview the emphasis shifted to difference and deficiencies. For example, Steve;

‘I don’t see a power thing in it, everybody is equal to me and if I saw a power thing there I would leave because I look at everybody the same, in fact some of the clients I work with are more intelligent than I am.’

And;

‘I think there is a level of understanding with clients with a learning disability that, it does stop, and I’m not being unkind.....but I think the development of their minds or their brains, it does stop.’

For some, the attempt to describe the normality of clients was attempted via questioning normality itself. For example, Andrew;

‘Basically, we don’t know what a human being is, that’s a pretty core belief with me, so what I mean is, from what little I’ve read of psychology, there’s a large unaccountable element for how a person actually is.....So in that

sense I see us all as equal and unable to make presumptions about anybody although we do all the time.'

Or by devaluing what is normal, like Gina;

'Yeah, it would be great if we could just help people to be as normal as possible but it's not like normal is so special, is it? Normal is often greedy and horrid.'

Emotional connection versus Detachment from client

This theme centred on the seeming need for respondents to feel a sense of connection with the client. This typically involved some sense of reciprocity and recognition from the client. The counter to this was a feeling that the client was not aware of the respondent. For some respondents, a perception of connection was a defining moment in changing their view of the client; For example, Freddy;

'I think the first time he smiled at me was quite a major thing for me, because it just seemed to be a smile of recognition. Maybe I was reading that into it but it had never happened before and this was nearly a year. So that was quite a major thing and it really meant a lot to me.....I think rather than just being this person I had to work with..... and do things to him, just physical maintenance, suddenly I warmed to him in a more personal way.'

Perceiving that the client is aware of the respondent and can share in their world seemed to be the times when most respondents particularly enjoyed being with the client. For example, Gina;

‘Today, after we’d been walking for about twenty minutes, he put his arm through mine and started singing...well, it’s a wordless tune, and I was singing with him and we walked along just singing with our arms linked which was really nice. Even when we got back to the minibus and he took his arm out of mine, he then just put his hand on my shoulder which was a very nice, gentle sort of gesture. Really, it’s nice when he comes back to us in that sort of way because he can go a very long way away.’

Respondents also described the sense of connection that arose from involvement with families. For example, Freddy;

‘his parents and immediate family really value himand just seeing that he’s needed makes you feel you’re part of something. It helps you connect with them a bit more’

For some respondents, there was also a sense of having their own needs for acceptance met. For example, Steve;

‘working in learning disabilities, the clients are very trustworthy of people and don’t find fault in you, they find good points in you.’

Seeing Client as a Person versus Not a Person or Part Person.

This theme arose mostly out of discussion in the interviews about how other people see the clients. For some, the emphasis was on not seeing the person at all beyond the disability and was a common perception of the view of the general public. For example, Alf;

‘When people see people in wheelchairs, they don’t see the person, they just see the wheelchair and that can be very, very frustrating for the carers.’

Not seeing the person was also an inferred attitude of some outside professionals and was contrasted negatively with professionals who did see the person. For example Kerry;

‘They see the clients as clients, not people. I know that’s their job but the one I have in mind, they’ve taken that job and think they’re better than the clients. The psychologist on the other hand is very, very good. The client has one to one with the psychologist....they have a lot of respect for that person.’

Some respondents had an understanding of the professionals' views but still felt they only saw a part of the person. For example, Gina;

'I recall one piece of work that one of the community nurses did and he had to go on the minibus, this person, because of serious problems that were happening on the bus, and it seemed like all he's doing is seeing this bad, this very difficult bit of behaviour. He didn't see the other bits, like I know that bit's bad and it was all to do with what is the appropriate way to be transporting him and, quite right, we needed someone outside to look at that to make it better. But you thought, if only he'd seen him elsewhere in other situations, he'd get a wholer picture.'

However, the dichotomy was also apparent within individual respondents, at times indicating they saw the whole person, at other times, not seeing the person. This was especially so of the change in their perceptions over time. For example, Shelly, speaking of the general public ignoring the client;

'...and that used to make me quite angry because by that time I'd spent so much time around these people that I knew them as people.....I think it is fear of the unknown. I mean because I'd never done this job before, I was a little bit like that myself when I first met the clients. It was only my managers' influence that made me see these people as genuine human beings.'

Negative perceptions and feelings versus positive perceptions and feelings

Negative feelings and perceptions were apparent when respondents talked of the reactions of others to the clients, particularly the general public. There were many examples of this and they covered a variety of emotions: pity, fear, shock, embarrassment and sadness. For example, Annette:

‘With X specifically it was very much pity because he ...never did anything that would upset anyone. Whereas another chap...he used to grab people, little children, and that was scary for people... I felt so annoyed at both those reactions really. There’s no happy medium between those two.’

Although anger and frustration at these attitudes were common, some respondents also showed sympathy to the reactions of others. For example, Gina;

‘I can understand it because I haven’t always worked with people with learning disabilities and when you meet up with someone whose behaviour doesn’t fit the normal thing you just think ‘that guy looks odd, I’ll be careful.’

However, although negative emotional response was commonly perceived in others there was also a tendency for respondents to describe negative feelings in their own first encounters with clients or prior to contact. Over time more positive views emerge,

mediated by a perception of a developing relationship and seeing the client as an individual. This links with the theme of seeing the client as a person. For example, Annette;

‘I mean when I first met him I thought ‘I’m not going to be able to cope’ because he looked so dependent.....he looked so helpless sitting there in a chair, dribbling.....and I don’t think he changed over time, what changed was my perception of him.....I started thinking of him as a personality because he was a lively individual who liked music and going out.’

And Kerry;

‘We had the variety buses come to our school and I had this one girl with me.....She did scare me a bit and I took her into the main hall and she had an epileptic fit and I just felt so helpless.....I mean when I was very young I couldn’t see the point of them being alive, that’s a very fascist view but I used to think ‘why don’t they just get rid of them all?’.’

The idea of being ‘got rid of’ had arisen earlier in the interview when Kerry described the mother of a client thus;

‘She told the rest of the family he was dead so she won’t be seen in public with him.....it makes me really angry that the mother is not enjoying her son for the more positive points he has.’

For some respondents negative feelings are described not only when talking about first contact, but in the day to day work with the clients'. For example, Freddy;

'I hated being out in town and I used to get incredibly embarrassed by incidents, you know, in a supermarket or café, people doing the most outrageous things, it used to really crush me sometimes, and it would make you really embarrassed and really angry at that person, even if they weren't aware of what they were really doing....you could end up really hating someone for putting you in that situation.'

Interestingly, earlier in the interview Freddy had talked of outrageousness and embarrassment, but in a positive way;

'People would look at us because he would be quite loud.....but I never felt embarrassed by him. I think sometimes people feel quite tense when they're out with people but I got to the point where I enjoyed his behaviour, even though it was a bit outrageous.'

For some respondents, perceiving negative aspects of the client led them to feel that their view of the client had been damaged in some way, although there is an attempt to recover the positive perception. For example, Andrew describes a nightmare he had on sleep-in duty about a client who could be aggressive smashing up the house;

‘And I woke up and she was in the kitchen, not smashing things up actually but just sitting there and there was that horrible latency of you know, yes she could suddenly, menace is the word I’m looking for and I found that challenging in a psychological sort of way, it was nasty, it felt a bit twisted, unpleasant, like a horror movie come true.....it damaged my perception of the client for a while....then happier experiences come along and you can see the more positive side of the person and that balances it out.’

Some respondents coped with the difficult behaviour of clients, especially when directed towards themselves, by attributing it elsewhere and not taking it personally. In this way positive feelings remain intact. For example, Shelley;

‘Occasionally, if you did get caught in the firing line he would grab whatever he could on your person. I don’t think it was actually aggressive towards you, but I think the way he was feeling, he just wanted to grab hold of something and unfortunately it could be your hair and he may attempt to bite your head. But I always got the feeling you were in the way of his anger, it wasn’t particularly directed at you and he was generally a really good guy.’

For Gina, this goes further, with the negative behaviour being interpreted as positive;

‘He sometimes bites but the biting is an affectionate thing not an aggressive thing. It’s quite rare for him to bite, it doesn’t happen that often, but it’s not an aggressive thing. I remember trying to explain it to his mother one time when he’d bitten and she was shocked but I said ‘don’t worry, it’s not aggressive.’

The positive/ negative dichotomy is also expressed in terms of respondents feeling they are doing good, improving the clients’ quality of life. For example, Annette;

‘That’s the best bit, you’re doing stuff and you can see you’ve helped that person to where they wanted to go.....they’re doing something that’s good for them so it’s a sense of satisfaction.’

But again, conflicting feelings come in, even on the level of feeling that one is doing good for the client, as elsewhere in the interview Annette says;

‘finishing a shift and going home thinking ‘have I actually improved that person’s life today or have I just made a mockery of it really?’

Client as Child/ Client as Adult

This theme arose mostly when respondents were talking about the way families saw the clients. For some respondents this was a frustrating experience. For example, Tracy;

‘They see them as children who need everything done for them, can’t make their own choices, highly protective sometimes.....I think families underestimate them, ‘oh, they can’t do that’. Haven’t allowed them to develop.....I find it frustrating when you know someone can do things but again, when they turn 18, the difficulty lies when service users still live with their parents when most people would have left home.’

Although some other respondents also found this attitude frustrating, there was also sympathy toward the family view. For example, Gina;

‘Some tend to keep, not intentionally I’m sure, but tend to treat the person as a child and again, I suppose you can see where it comes from. You’ve given birth to somebody who apparently has not grown up into an adult.....that most people perceive of as an adult in the sense of independence. So I can see that must be very, very, difficult.’

And Steve goes further, feeling positive towards this attitude of families;

‘One set of parents, they used to visit regularly. They come in and they see their child as a child and the way they communicated with him was very much like a father/ son or mother/ son thing and I liked that in a way because you could see the connection between the parents and the service

user, which you don't see with a member of staff and a service user and it's an in bred thing in there.'

Although respondents preferred to see clients as adults, there were also examples of them perceiving childish qualities in clients. For example Kerry at one point describes a client as childish and later expresses anger with a family for doing the same;

'He's still very childlike, I'd say in the things he likes. He likes young boy's toys like cars and teddy bears.'

And;

'I think they treat him like a little child really....it must be difficult for them because I think that's the limitations of their understanding but at the same time I can't really stomach their prejudice'.

Gina struggles consciously with the adult/ child dichotomy;

' There's one mother who gets a lot of soft toys ready for her child, well not a child, when she gets home and maybe it's time to ease up on that. I mean, it's very difficult though because if it gives a person comfort then why the hell shouldn't they have that. Age appropriateness is fine in theory but you can only start where people are.'

Locating Self with the Client

This theme arose from respondents describing how they relate to the clients. Some respondents described a relationship akin to friendship and involving a degree of attachment. For example, Freddy;

‘When I used to be walking in town with him, I felt just like I was out with a mate, going out on a Saturday. I never had this feeling I was out with this person in a wheelchair.’

Annette was more explicit about friendship:

‘I’m talking now as his friend...’

and describes the intensity of feelings that can be involved;

‘I worked with him, we all worked with him very closely, it was really intense work and you do really feel you are their sole person, you get really attached. I got really attached to him and others in that house.’

And Steve goes even further, suggesting a feeling of belonging with the clients akin to family membership;

‘Now I look at it as part of everyday life, and very much like they are family to me, in fact, in some respects closer than family, because you

don't have that fighting you have in families...all those different opinions from people in families. It's very mutual, very laid back, very easy going'

Steve also locates staff with clients in terms of who is in need of help;

'It's interesting because the people that work here are all very, very, different but they all seem to have one common denominator, and that is they all seem to need the help as much as the service user. They need that experience for some reason in their private lives.....

A sense of identification was also expressed by use of language that put the respondent and the clients in the same group. For example, Shelley, talking about the views of the public:

'I think they prefer them out of sight, out of mind, to be honest. That's the way I felt people thought about us.'(author's emphasis).

Others appear to locate themselves with the client not as a friend, but as an advocate.

There is more distance as the respondent is perhaps 'next to' the client, not with them as an equal, but still much closer to them than others are perceived to be. For example, Gina;

‘I suppose whenever I’m talking with someone like that about a client, I’m trying to explain them so much, to try to convey my picture of that person, I suppose.’

For some respondents, a threat to the perception of clients as equal came from perceiving a power difference between themselves and clients. Steve, quoted earlier, refused to see a power difference, saying he would leave the job if he did. Freddy, quoted earlier as seeing a client as a ‘mate’ says later;

‘I ended up working with that client group and there were aspects of it I found very difficult.....like doing actual physical care to people. I just never liked having that kind of power over people, although it had to be done’

Influence of Colleagues, Teams and Care Philosophy

This theme describes the external influences that respondents were aware of on their view of clients and the work. For most respondents the positive attitudes endowed by these influences were tempered by the realities of the work. Some described the affect of the philosophy of teams they worked in as very powerful. For example, Shelley describes a process of observation leading to an internalisation of the values and practices of the team;

‘When I started there were two managers and I thought ‘wow, they are so intelligent and compassionate’ and you know, they didn’t drum it into me

but I just watched the way they worked with the clients and I owe so much to them because the way I am now, they moulded me.... And the other staff were just incredibly enthusiastic... and never once said 'oh, he wants a cup of tea.'. It was always 'so and so, would you like a cup of tea?' And I couldn't not talk to someone directly because I'd be the only one. Suddenly it became natural to talk directly to someone'.

Shelley is describing being a new member of an established team. Freddy describes the shared values of a group of staff starting together in a new project;

'Being part of an original project to get people into the community whatever their abilities were, initially we were quite evangelical about it and thought that we were really making a big difference and everyone would notice that these people were part of their communities.'

Freddy goes on to question this 'evangelical' attitude;

'I think I've become a lot more pragmatic over the years and a bit more, I suppose, cynical as well, that maybe in some respects we've come as far as we can.....I've learned not to be so evangelical about it. I think initially we were all very fired up and made an awful lot of mistakes.'

Tracy also refers to a belief in a care philosophy but again questions it, this time in terms of people not putting it into practice properly;

‘I have similar values to the one’s social services have, the five accomplishments¹ but it’s all very well having these beliefs and I have got them but how do you make them work? Because they’re a team thing, every single individual has to follow them. And every single individual doesn’t.’

Tracy describes the influence of staff and teams on her own views mainly in terms of negative examples of staff behaviour contrasting with her own views, as does Annette when asked what most influenced how she saw the clients and the work;

‘How the staff treated the clients. There’s a big difference, because if you did have staff who didn’t have any concept of treating people in the way that I and lots of other staff did, it made the shift difficult. If I wasn’t working directly with a particular client and I saw they weren’t being treated in the way I felt they should, then it made my life difficult and I was thinking it must be making the client’s life difficult.’

But Annette also struggles with the conflict between the philosophy she believes in and the day to day reality of the work and does not seem able to resolve the conflict. Talking of the importance of giving choice to the clients she says;

¹ O’ Brien’s (1987) five service accomplishments of community presence, choice, competence, respect and community participation

‘We would ask X what he wanted and try to give him some choice but he never really could choose. We believed it was the best way to be because normalisation, it was the way, we believed it was the best way to be, in that way recognising he was a human being first....it was stressful because you feel like you’re trying to encourage someone who possibly, it doesn’t matter to them in a way. But it matters because they’re human beings....but sometimes it feels a pointless task. So the normalisation process should be applied to everyone who has a learning disability, not just those who can choose.’

Steve describes the pressure of being aware of other staff members’ judgements of his attitudes to clients;

‘I think you are very conscious of how other staff perceive you as well. Are you being childish with clients? Are you being demeaning? All these things are constantly on your mind and you’ve got to weigh it up with other staff members.’

A Typical Account: Shelley

In order to bring the above themes together and show how they relate, the following is a summary of one respondent's account. It is chosen as an example of a typical account, that is, the themes expressed are similar to most of the other respondents.

Shelley's written description of the client stresses communication problems but covers other aspects of the person such as personality and likes and dislikes. She is very positive about the clients. Shelley began working with the client group with trepidation and felt 'frightened of' the clients, perceiving them as 'not like normal people'. She did not see them as 'genuine human beings'. She was motivated by a desire to help clients 'have a good time'. She also feels she got a lot out of the work personally. Over time she feels she came to know clients 'as people.' This occurred as a result of doing things with clients, feeling a sense of 'bonding moments'. She moved to a position of being alongside the clients, describing herself and clients as 'us'. She got to know things about the clients by detailed observation but feels she 'hardly knows anything'. She was strongly influenced in her attitudes by her colleagues and managers, who 'moulded' her. She struggles with the perceived attitudes of others, that is, public 'completely ignoring' clients or being 'terrified', parents treating clients 'like a great big 3 year old'. However she has some sympathy for these views. She felt some outside professionals were good, some bad. She was less sympathetic to the negative views of outside professionals, feeling they should know better.

An A-typical Account: Tracy.

This is chosen as a-typical because although Tracy did share some themes in common with the other respondents, the whole tone of her account was different, in that it was quite negative and pessimistic.

Tracy's written description focuses heavily on the client's disability. She is quite negative and pessimistic in her description of the client. She was drawn to the work by wanting to help but feels it is quite futile because of drawbacks in the service. She is not happy at work and is distressed about the working practices of many of her colleagues, feeling that client's rights are being ignored and abused. She is very aware of power differences and the disadvantage these differences confer on clients. She describes no moments of emotional connection in her work and feels both that she is not fulfilling client's needs or feeling fulfilled herself. She locates herself with the clients as an advocate against the negative practices she perceives, but feels she has failed and cannot make a difference.

4. Discussion

4.1

The Written Descriptions

Although the descriptions shared some factors in common with general free response descriptions, such as personality traits, activities, likes and dislikes, appearance and abilities, the most common categories were the disability itself and communication issues. Neither of these categories would be found in ordinary free response person descriptions as outlined by Fiske and Cox (1979). However, this may partly be to do with instructions given to participants. Asking for a description to ‘give an impression of that person’, they may have felt that the investigator, as a stranger, needed to know about the disability. This does not necessarily mean the respondents themselves felt it was the most salient fact about the client.

Regarding communication issues as part of the client descriptions, as the interviews proceeded to show, issues and difficulties around the area of communication were very salient for the process of how clients were perceived. Communication as a process seemed difficult to divorce from communication issues as facets of the clients themselves in the descriptions. Respondents seemed to view the various behaviours of clients as communications, in a similar way to that described by Siegal-Causey and Downing (1987). However, because of lack of communicative intent on the part of clients, the onus was on staff to interpret these behaviours and give them a communicative significance. Failure to do this was very frustrating for staff. Their extensive efforts to interpret and

make sense of clients' actions and moods suggest staff/client relationships similar to the 'meaning-maker' type encountered by Clegg et al (1996). Interestingly, in the Clegg et al study, one staff member operating in the 'meaning maker' mode describes this task of interpreting and making sense as 'someone inside the client trying to get out'. This was not pursued in the Clegg et al study as it was not the focus. It is, however, an interesting echo of what developed in the current study regarding looking for things 'below the surface' or speculating about unknown abilities.

It is important to mention that in the present study, respondents were asked what they felt they did not know about the client. Therefore, it could be argued that the dialogue regarding what is known or uncertain is an artefact of the interview. However, respondents actually began talking about knowledge and uncertainty before this question was asked, especially around describing how they interpreted clients' needs, wants and feelings. Asking directly about what was unknown then took the focus more onto speculation and fantasy.

Another category that emerged that is not usual in free response descriptions was that of emotions. As Zebrowitz (1990) points out, the non- inclusion of emotions in most free response person descriptions probably reflects the nature of instructions which seem to call for information about enduring characteristics. The difference for the respondents in this study seemed to be that tracking client's emotional responses and reactions moment to moment is a key feature of how respondents get to know most things about the clients, including wants, needs, likes and dislikes. In this sense, in order to perceive more

enduring traits, tracking of emotions is necessary and becomes part of the content of descriptions.

4.2

The Dichotomous Themes

The emergence of seemingly contradictory statements and themes is a phenomenon that can be seen in other research where attitudes to devalued groups are being considered, and is often a key feature of discourse analysis. For example, Potter and Weatherell (1995) give examples of interview extracts where white New Zealanders, talking about the Maori population, move between ideas that could be described as racist and those that are anti-racist. These ideas occur in disparate parts of the interview. Potter and Weatherell argue that this variability is problematic for social psychologists trying to work with some form of attitude theory, looking for underlying and fixed cognitive maps. They further argue such variability is predicted from a discourse approach, as people perform different actions as they speak, for example aligning with friends and distancing from enemies. In the research presented here, one could argue that this is what was taking place, as respondents sought to make sense of clients, defend clients, and position themselves, clients and others in their social and emotional worlds.

To describe the way some of the dichotomous themes seem to work in respondents' perceptions of clients and where the conflict arises, it is perhaps useful to conceptualise them as a change over time in the history of the respondents' relationships with clients. This also shows how the various themes interrelate (see figure 1 for a model of this process).

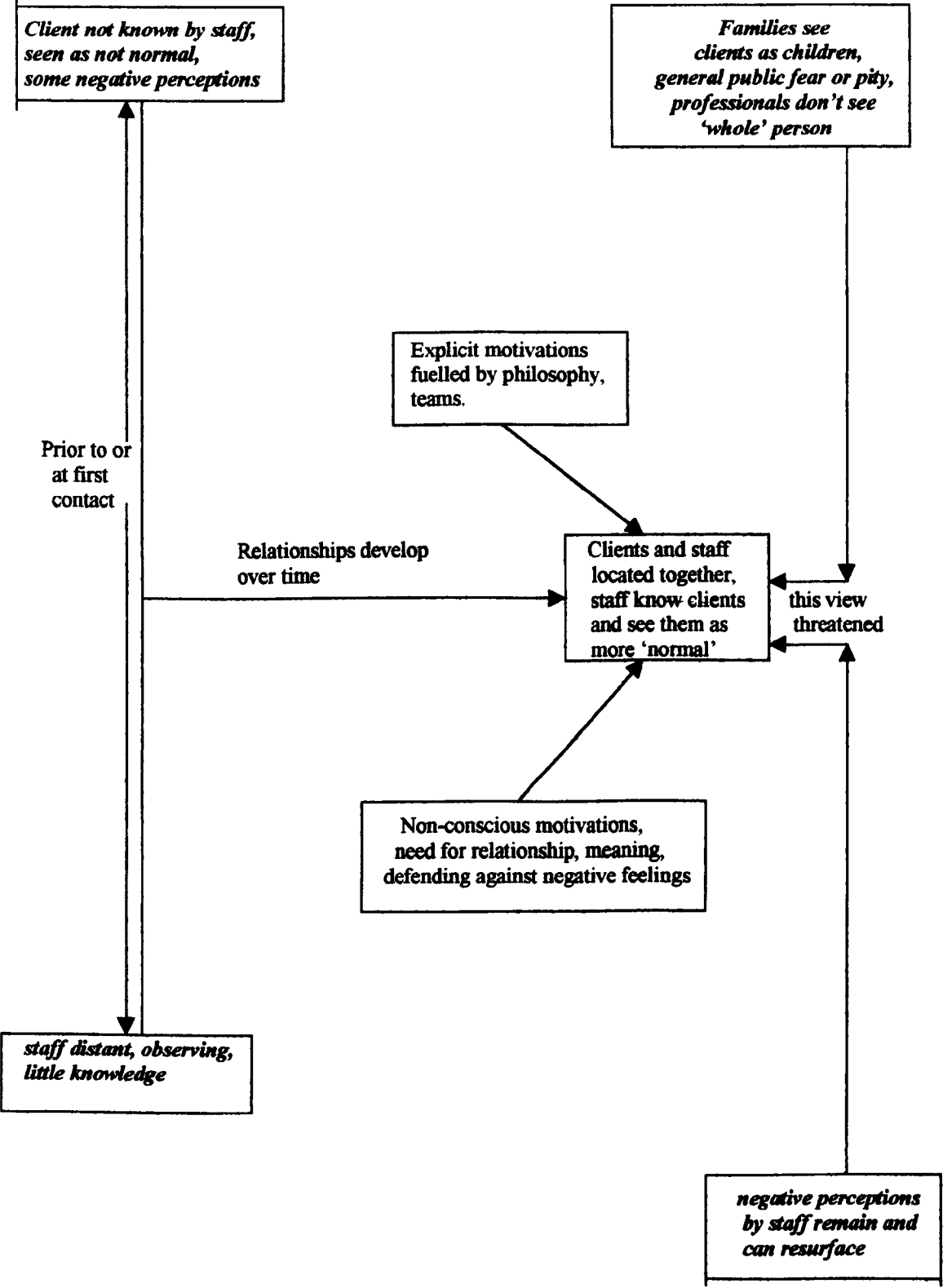


Figure 1: Changes in perceptions of clients over time and areas of tension (shown in bold italics).

At the beginning or prior to the beginning of contact, respondents have some negative perceptions and feelings regarding the clients, whether this is fear, pity, hopelessness, sadness or shock. Some see the clients as very different to normal and not as a whole person. They also feel they do not know the client. Over time, they get to know more about the client, both from interaction and observation and via others who know the client. They have times when they feel connected to the client emotionally and these shared experiences help them to see the client as a person and as an individual. This process can also be partly fuelled by external factors, such as care philosophy and team attitudes that reinforce the desirability of seeing clients as 'normal'. This process is aided by the fact that so much about the clients appears to be unknown, leaving a great deal to be guessed at. As Fiske and Neuberg (1990) suggest, when information about the target is ambiguous or limited, the values of the perceiver play a large part in how a person is perceived.

As a result of the above processes, respondents then seem to locate themselves in an 'ingroup' (Tajfel, 1970) with the clients (and other staff) and feel closer to, and more understanding of, clients than those perceived to be outside this group.

It was perhaps significant that Tracy, whose account was different in that she seemed negative about the client and the work in general, felt alienated from this type of group membership. She felt alone, fighting a losing battle, and her perceptions of the clients

were hopeless. She felt she did not belong and was not part of any collective endeavour. Perhaps in order to maintain positive feelings about the clients, it is necessary to feel part of a collective, positive 'ingroup'.

However, as the interviews showed, it is not a simple move from one axis of each dichotomous pole to the other axis over time. Although movement has taken place, it is not stable and there is oscillation between the poles. Although respondents grow in knowledge about the clients, uncertainty always remains and can be very frustrating. The original negative perceptions can return at times and are hard to acknowledge now the client is seen 'as a person' and sometimes as a friend. Striving to see the client as normal is juxtaposed with awareness at times of clients being very different. The need to try to stay with the 'positive' poles is brought up when 'outside' groups such as professionals and public are perceived by staff as seeing the clients in a negative or incomplete way.

The way these processes take place seem to involve an interaction between inner and outer factors, conscious social processes and less conscious or unconscious processes. As discussed in the introduction, perception is heavily influenced by the motivations and goals of the perceiver (Snyder, 1998), and these can be both explicit and non-conscious.

Relating this back to the literature on stereotyping, Devine (1989) argued that all people initially react to devalued groups in similar negative ways. What distinguishes low prejudiced groups is that they engage in subsequent conscious cognitive activity that makes them reject their original reactions. In a similar way, respondents here rejected

their original reactions. Their subsequent conscious restructuring is partly fuelled by social processes such as learning from other staff and transmission of shared values, as well as powerful care philosophies. These processes emphasise an equality between client and carers. This may help care staff in addressing the issue of how to define their relationships with clients. Respondents clearly did not feel happy with 'carer and cared for'. However, this equity is often contradicted by the reality of the work

On a less conscious level, there appeared to be a need for meaning and emotional connection with clients in order to make the job enjoyable. As was discussed earlier, there is a need for equity and reciprocity in relationships generally (Duck, 1994) and respondents seemed to strive to find this in their work with clients. Returning to the initially negative perceptions by respondents of clients, perhaps as Sinason (1990) suggests, the feelings engendered by encountering the severely disabled are sometimes too painful to bear. Infused in an atmosphere of positive philosophy, it can be hard to own and express feelings of damage, grief and fear. What seems to happen with some of these respondents is that these feelings become cut off and unacknowledged but can reappear at times, causing great stress and emotionally charged reactions. Recall Andrew's horrific dream of latent aggression that left his view of the client damaged. Or Freddy, trying to be positive about clients with difficult behaviour, yet at some points feeling utterly crushed by such behaviour and even hating the clients on occasions.

This does not mean that positive feelings do not really exist or are some sort of 'cover up' for the negative ones. As Potter and Weatherell (1995) argue, apparent contradictions in

attitudes make sense if one sees them as respondents trying to make sense of their world and making decisions about where to locate themselves in relation to clients. Respondents were enthusiastic about the clients and the work generally and there is no doubt that this is genuine. What does seem to happen is that the less positive perceptions and feelings are more difficult to own, and it seems hard to maintain a positive view of the clients whilst at the same time acknowledging difference and difficulty. This is a constantly dynamic process that seems to cause tension. It is also true that some respondents were aware of these tensions and had obviously thought about the issues before. However, even with this awareness, the tension remains.

4.3

Personhood

Struggling with the personhood of clients came across strongly in some of the interviews. It was perhaps surprising that respondents so invested in presenting the positive could own views such as 'I used to think they should all be got rid of' and 'I didn't see them as genuine human beings.' As Sanders (1995) argues, where one locates individuals and groups on the gradient of personhood has important consequences. Those construed as non- persons can be routinely disposed of. Those construed as persons are seen as having needs and rights. In the light of the history of non-human status that has sometimes been conferred on the severely disabled, there is a real fear of the consequences for non-personhood. This may explain the need of people who work with the profoundly disabled to over- compensate for the disability and inflate the 'normality' and abilities of clients in order to confer personhood and make it secure.

This debate obviously goes way beyond the remit of this research and care work, but it is important to highlight the social influences which inform this debate. Society regularly struggles with the concept of personhood and there always seems to be a tension between conscious and unconscious factors. Models of disability are socially and consciously constructed and the less conscious, perhaps more uncomfortable, feelings are difficult to incorporate and discuss, again because of fear of the consequences. If all human life is accepted as having intrinsic worth, this relieves us of constructing categories and grades of personhood. If, however, there is a gradient, we always have to justify who is included and who is excluded. For example, it is generally accepted that there is good reason to abort severely disabled fetuses, but how then do we live with the ongoing ‘damage’ presented by living, adult, profoundly disabled people? As this research has shown, even amongst those most committed to seeing the profoundly disabled in a positive light, difficult feelings around damage and difference proliferate.

4.4

Critical Review

The use of semi-structured interviews seemed to work well, in that respondents talked openly and at length. Respondents reported that questions were appropriate and enabled them to speak openly. Prompts were useful in order to address the research questions but respondents also brought in many observations and perspectives that went beyond the questions on the interview schedule. All the data on conflicting perceptions and feelings within respondents arose without any direct questioning on these issues.

Although some themes were closely related, inter-rater reliability was good, indicating that themes could be distinguished. Inter-rater reliability for the analysis of the written descriptions was also good.

The number of participants was small. This had the benefit of making the data more manageable and gave a quality to the analysis of interviews that kept individual respondents in mind at the same time as looking for commonalities. The drawback to the small participant numbers was perhaps less variability amongst participants than one might achieve with a larger sample. This has implications for generalisability.

It is also important to point out that the participants were a self selected group, all of whom were interested in the research and keen to take part. They were also all from one county. For these reasons, it is safe to assume that they are not representative of all care workers with this client group. As the interviews showed, most of the respondents had worked in services where attention was paid to philosophy of care and where the job was seen as much more than simply caring for basic needs. All respondents had worked in statutory and voluntary sector services and none worked in the private sector. It is likely that there are many establishments where workers show less concern with the difficult issues raised in this research, who see the job as mainly one of practical care, perhaps akin to Clegg et al's (1996) 'provider' type relationship discussed earlier.

On the other hand, it could be argued that respondents might represent at least a particular sub-section of care workers in this field of work. As respondents were from various

service settings and had a variety of experiences, they were not representing the sort of group view that may have been obtained from workers in just one service.

The definition of ‘profound learning disabilities’ in the selection of a client to talk about was quite subjective, even though some guidance was given. This was kept fairly loose because the aim was to focus on the respondents’ perceptions and the processes involved rather than details about clients. To this end, the selection of a particular client was to focus the interview and find a way to explore these processes. Within the bounds of this research project, there was not an opportunity to ‘screen’ clients. However, all of the respondents worked in services for people with profound and severe learning disabilities and it was clear that the clients they discussed had considerable disabilities. For example, eight out of the nine clients selected had no language. However, it must be recognised that there could have been considerable variation between clients being discussed.

Finally, it must also be noted that no respondent validation of the results was sought. This was partly due to time constraints and the fact that in the participant information sheet there was no indication that any further involvement by participants would be required. There was also a concern that as many of the themes appeared to involve conflicts that were less than conscious, participants might have found presentation of these distressing. Although brief feedback was given, it was felt that to go into the results in depth with participants might have raised issues needing further input. As will be discussed later in this section, the bringing into awareness and validating of these difficult feelings and perspectives is an implication for clinical practice, and needs to be done with sensitivity,

planning and support. However, as some feedback to participants was given, it would have been useful to get a response to this and would have undoubtedly added to an understanding of the processes involved.

4.5

Implications for Clinical Practice

Before considering possible implications for practice, a brief word is necessary about who is targeted. The difficult issues raised are not just pertinent to care staff, who can then be seen in need of help from others who do not struggle with such issues. The reason these conflicts arise so strongly for care staff is because they become involved, they do the job, having extensive contact with clients day to day. The issues are, however, pertinent for all those involved with the client group, and arguably, pertinent for society generally.

For some staff, there is obviously enormous emotional involvement with the clients and the work. Difficult feelings are hard to acknowledge as staff feel they are 'defenders' of the clients. Also, to acknowledge fears of hopelessness and meaninglessness in the work could make the work intolerable. Staff may benefit from a forum to bring up and discuss difficult feelings. As discussed earlier, a systemic approach in care facilities is not often considered. Clinical psychologists could have much to offer here. However, this has implications for groups of professionals, including clinical psychologists themselves. Such professionals may also defend against difficult feelings by, for example, isolating and treating particular aspects of the client such as behavioural difficulties. Therefore, such professionals are part of the system that needs to acknowledge and discuss difficult

feelings, but perhaps are better placed to be aware of the issues and get the process started. The purpose is not necessarily to look for solutions to these difficult issues, but to give permission for them to be aired. This may have the benefit of reducing the tension that can arise between care staff and visiting professionals, who are often perceived as having a very different view of the client. If complex feelings can be acknowledged, staff may feel less threatened by the views of others. However, this is not to suggest that the airing of such feelings be compulsory. Care staff may cope with difficult aspects of the work by cutting off certain thoughts and feelings at times. This is something we all do and needs to be respected.

Perhaps what should be sought in this debate is something akin to the position of 'safe uncertainty' as described in therapeutic practice (Mason, 1993). Focusing on family therapy, Mason outlines a framework for thinking about dilemmas in therapy. Mason argues for a position of safe uncertainty, which is always in a 'state of flow' and allows new explanations to be placed alongside, rather than instead of, explanations that are brought by therapists and clients. This does not mean that therapists cannot acknowledge any expertise. This would be disingenuous and may lead to a position of 'unsafe uncertainty' (Mason, 1993) where the client feels overwhelmed and uncontained. What is suggested, however, is that there is a move away from seeking solutions so that a position of open curiosity is maintained.

Translating this position into working with staff, as many of the dilemmas have no solution just being able to say this could reduce distress. Paradoxically, once this is aired,

new solutions may be found as a result of open, honest exchange. What is lost is the belief that there is one solution, the position of 'safe certainty' that so many look for and professionals try to provide.

Being able to talk about difference is also crucial if one is to identify what can be changed and what cannot, where it is best to locate energy and resources for helping the clients. As Sinason (1990) puts it, 'some differences are not fair and need to be socially tackled. Some are not fair but cannot be changed.' Being unable to talk about difference regarding clients can lead to very 'topsy-turvy' decisions being made. For example, the present author was involved with a care home where one client was not allowed by staff to have beans on toast for dinner on Christmas day, even though she said she did not like Christmas dinner. Regarding the same client, staff disagreed with a recommendation to put an inside lock on the front door, even though the client, who had a severe learning disability, had been found in the road some distance from her house, had no road sense and would also approach men. Both these decisions appeared to have been made on the basis of what was 'normal', that is, to eat turkey on Christmas day and to have freedom to come and go from the house. Being unable to acknowledge and discuss difference prevented a clear view of the best approach in these circumstances; allow the client to exercise choice where she was able (in choosing food) and protect her where she was at risk and could not make an informed judgement. However, it is not enough for the clinical psychologist or others involved to merely tell staff these things, as the acknowledgement of difference may bring into focus the difficult and painful feelings discussed earlier. These issues need sensitive handling.

Smith and Brown (1992) argue that conflicting feelings dating from infancy are activated in the caring role. In order to push away the pain and anxiety these feelings engender, they can be projected onto others. Smith and Brown point out that Wolfensberger (1983b) saw the making explicit of negative feelings as a prime motivator of change within the normalisation philosophy. However, Smith and Brown argue, the normalisation movement have located the problem in a historical and social context, not attempting to trace the development of negative feelings in the internal worlds of people who work in services or in the experiences they bring to their work.

Smith and Brown (1992) argue powerfully for the need for workers in this field to be able to express ambivalent feelings regarding the work and the clients. Without the opportunity to do this, unacknowledged feelings can leak out, possibly in a way that could put vulnerable clients at risk.

However, if clinical psychologists are to play a role in raising awareness of these issues in working with the learning disabled, it may be useful for them to look at their own motivations and conflicts. There has been little individual psychotherapy with clients with learning disabilities (Bender, 1993). Both behaviourism and normalisation have focused heavily on environmental factors. Psychometric testing has been seen as a means of labelling people negatively. This has meant that services available to the wider populace, such as diagnosis and monitoring of degenerative neurological conditions, have not been

available for people with learning disabilities. Recently, however, things have begun to change with, for example, the setting up of screening programmes for dementia in learning disability services. Tools for assessing cognitive ability and change such as the 'severe impairment battery' (1993) have been shown to be effective in assessing cognitive functioning over a wide range of ability (Witts and Elders, 1998). Tests such as this can be used in assessing deterioration associated with dementia in people with even severe learning disabilities.

As changes in people's abilities and functioning over time have crucial implications for their future care needs, neglecting this domain can have very negative consequences. McCarthy and Mullan (1997) point out that the population of elderly people with learning disabilities is increasing, with the attendant problems associated with ageing, such as dementia, sensory impairment and mobility problems. Also, it has been shown that dementia occurs at a higher rate among elderly people with learning disabilities than among the general population (Cooper, 1997).

What seems to be involved for many of the various people in contact with clients, carers and other professionals, is an aversion to discussing the disability itself and its implications for the individual. Returning to the history of attitudes to learning disability, perhaps it is inevitable that the pendulum has swung so far away from seeing the disability as the only relevant factor. This had to happen to challenge what had gone before, when the disability was seen as the totality of the person. Things have, however, swung towards it being difficult to acknowledge the disability at all. This position

removes the possibility of acknowledging both positives and negatives in disability; the right to feel positive about being different, as discussed by Szivos (1992), and the real distress and difficult emotions that can arise from having a learning disability, as discussed by Sinason (1990). Whilst emphasising environmental factors has undoubtedly brought benefits to the lives of many with learning disabilities, it has perhaps overshadowed the real difficulties that disability itself can confer. Clinical psychologists are well placed to put these factors on the agenda in an effort to find some balance. Ideally, the pendulum would eventually find some middle ground, enabling all those involved to focus on the real needs and difficulties of clients, environmental and personal, positives and negatives, with nothing being taboo.

4.6

Suggestions for Future Research

This study could be repeated with a larger sample, in particular extending the types of services respondents are derived from. As discussed earlier, one may find very different perceptions of clients amongst staff in services where care philosophy and staff practices do not encourage positive perceptions of clients.

As well as a larger sample, it would be advantageous to be more specific about the client group that is being perceived. In the Clegg et al (1996) study of staff relationships with profoundly disabled clients, clients were formally assessed using developmental scales. Obviously, if this were to be done, issues of consent would have to be examined more closely.

It would also be interesting to repeat this research with others involved with the profoundly disabled client group, for example, families and professionals such as clinical psychologists. In this way, the similarities and differences in perceptions of clients between these groups could be mapped. This could perhaps shed some light on where some of the difficulties in communication and working between these groups are coming from.

This research identified a number of rich themes that may bear closer examination as the individual focus of further work; for example, constructions of normality and personhood, the influence of staff peer pressure on how clients are perceived, and changes in staff perceptions of clients over time.

It may also be useful to look at the personality styles of people involved in care work with this client group. Some of the needs of the staff were apparent in this research project, for example, need for belonging, acceptance and to see themselves as doing good. If certain types of people are drawn to this work, it may be helpful to know this in terms of working sensitively with staff, where their strengths and vulnerabilities may lie.

Finally, and more generally, there needs to be more research on systemic approaches in learning disabilities, extending this from family groups to staffed environments. The way these respondents described their work, there was a very strong feeling of a system to which staff felt they belonged and which impacted on all members.

Conclusion

This study attempted to explore factors involved in care staff perceptions of profoundly learning disabled adults. Bearing in mind that conclusions drawn have to be tentative due to the limitations of the study, the interviews suggested that there is a tension involved in perceptions, as care staff struggle with potentially difficult feelings about the clients and the work. These feelings may not be easy to express in certain work cultures. Also, care staff can become very emotionally involved with the clients, feeling a sense of identification that can also make difficult feelings hard to integrate. It is suggested clinicians may be able to encourage exploration of these conflicts, whilst recognising that clinicians themselves are also implicated.

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LIST OF APPENDICES

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Title of Research Project: Care staff perceptions of adults with profound learning disabilities.

I am in my final year of a Doctorate in Clinical Psychology, training on the South Thames (Salomons) Clinical Psychology Training Programme. I have to complete a research dissertation and I am interested in investigating how care staff perceive and get to know clients who have a profound learning disability. There is little clinical research on the staff perspective in learning disabilities. It is envisaged that this research will contribute to the knowledge about staff/ client relationships as well as providing a deeper understanding of these issues for clinical psychologists working in this field. To undertake the research I wish to interview a number of people who have at least one year's experience of direct care work with this client group.

Interviews will be confidential but will be taped and should take no longer than an hour and a half. I will also be asking participants to write a description of a client they know well. In order to protect client confidentiality, I will ask participants to use pseudonyms for all clients they discuss and write about, and not to include any details which would identify the client. These might include rare medical or genetic conditions, descriptions of physical appearance, family details, where the person lives etc. I am interested in your perceptions of the client as a person so these details are not necessary anyway.

In the write up of the research, no names or identifying details of participants will be mentioned, although the pseudonyms given to clients may be used when giving examples of what participants have said about clients. Transcripts of tapes will also be anonymous. Only myself, my two research supervisors and two course examiner's will see the interview transcripts. They will not hear any taped material and will not be allowed to keep any material. All tapes and transcripts will be destroyed by September 2001.

After the interview, you will have a chance to give feedback to me on what you think of the process and to discuss any aspects of the process with me. You will also be free to contact me afterwards if there is anything you wish to discuss. When I have finished the project I will write a short summary of the results which will be available to you on request.

If you would like further information, please telephone me on 01273 696045. If you would like to participate, please sign the consent form attached to this sheet and return to me in the envelope provided. No stamp is needed. The decision to take part is entirely voluntary and you will be free to withdraw at any stage during the process. If you decide to participate, I will contact you and arrange a time and place convenient to you for the interview.

Thank you for your time in considering this

Yours sincerely

Sarah Kenny.

Consent Form

I have read and understood the information sheet .
I would like to take part in the study and I consent to be interviewed.

Name:-----

Signature:-----

Contact Tel. Numbers :Home:----- Work :-----

Any best times to phone you?-----

Interview Schedule

Instructions for written exercise

Think of a client you know fairly well (have known for at least 6 months) who you work with now or have worked with in the past. Take a few minutes to write a description of them in your own words. What sort of person are they? Write it however seems most appropriate for giving me an impression of that person. It should be someone who has a profound learning disability, who has little or no verbal communication and needs considerable help in all activities of living. They may have concurrent physical or sensory disabilities or autism in addition to the profound learning disability. Do not use their real name or include anything that may identify them such as where they live or work (day care) or very rare medical conditions.

Interview question areas

1. For each point in the written description, ask how they came to know that about the client? (ask for examples).
2. What was their first impression of the client when they met them?
3. How did their view of the client change over time?

Any specific events or situations that changed how they saw them?

4. How do they and the client communicate with each other?
Ask for examples.
How does the client convey needs, feelings;
How does respondent communicate feelings and intentions to the client.
5. How do they think the client sees the world?
6. What do they feel don't they know about the client?
7. How do they think other people perceive this client and other clients they have worked with?

General public?

Family?,

Outside professionals? (*ask which they have had experience of-suggest doctors, nurses, social workers, psychologists, speech therapists, psychiatrists, physiotherapists, occupational therapists*)

Why do respondents think these people perceive clients in these ways?

How do respondents feel about their views? (What about other clients they have worked with)

8. Thinking about their overall experience in this work, what sorts of things do they think have affected how they see clients? How have they affected them?

Experiences with clients?

Experiences of colleagues and teams?

Training?

Own values and beliefs?

- 9.. What brought them into this work originally?

Motivations?

Expectations?

10. What is the work like for them?

What do they get from the work?

What is good?

What is difficult?

TEXT BOUND INTO

THE SPINE



Ms S Kenny
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24 March 2000

Direct line 01892 507665
Direct fax 01892 507660
E-mail t.lavender@salomons.org.uk
Our Ref AL/1t/075/2000/sk2

Dear Sarah,

Thank you for your letter received 23rd March 2000 with enclosures.

We can now give Full Approval for your research project as you have clearly taken into account the points raised. For our records we would however wish you to send us the revised information sheet which was not enclosed with your letter. It will obviously be important to include the changes when you write up the research but we will not require you to submit a revised proposal.

We hope the project proceeds smoothly and look forward to hearing about the findings.

Yours sincerely,

Professor A Lavender
Chair of Ethics Panel

c. Nigel Armstrong
Dr Jan Burns

Research Diary

February 2000; I have to embark on a new research idea, my previous quantitative one proving unfeasible due to lack of statistical power. Research directly with clients in learning disabilities seems to be hard to set up. I have an idea for a qualitative project in learning disabilities involving staff. I feel very lacking in confidence as time seems very short and the process of getting started seems full of huge hurdles. My idea very basically is to look at staff perceptions of clients with profound learning disabilities. My interest in this has arisen out of two main experiences. Firstly, my own experience in care work with this client group led me to believe there was an inclination for staff to 'build' personalities around clients and project clients as normal. Secondly, my experience as a psychologist in learning disabilities has made me aware how often staff perceptions of clients are at odds with other professionals' perceptions. This can make a working relationship hard to establish, particularly as so much psychological work with this client group involves working with staff rather than with clients' directly.

March 2000; I have been struggling with my proposal and with getting my research questions right. I want to keep the questions open as possible, in line with grounded theory, but have taken advice that it is considered good form to have areas that are to be covered in the interview. A lot of the background for this is in social psychology, in the arena of social perception, a rather vague area for me, so I'm doing a lot of revision. There is little relevant research in learning disabilities, but I found an interesting paper that discusses a grounded theory account of the staff perspective in profound learning disabilities, focusing on types of relationships between clients and staff. It does not however focus on staff perceptions of clients and what is involved in arriving at perceptions, the area I intend to focus on.

March 22nd. Finally got ethics approval. Huge relief. Straight away hand out information sheets. I've got so much to do and feel completely daunted, even that it is not possible and I may have to defer.

April 2000; From the few interviews I have done so far I have been struck by the descriptions of a particular moment or event that is recalled when respondents felt their perception of the clients changed. These moments seem to have a quality of emotional connection or reciprocity in relationship which seems to be really important for staff, who feel afterwards that something has been broken through and they are seen as a person as well as seeing the other as a person. They feel with the client rather than simply doing to the client.

Feel a bit detached from it all really. Feel it is a shame that the pressures to get it all done detract from enjoying it. I am interested in the subject and the people, but the urge to focus on the number of tasks to be done is overwhelming. You just want to get it done rather than enjoy and experience it, which is a shame.

May 6th. Transcribing, transcribing, transcribing... It is hard work but I am so glad I am doing my own transcribing. It has really brought me back to the interviews and I

am finding it fascinating. Although still feeling immensely pressured, it has immersed me in the ideas again and helped to move away from that task focus. I haven't started analysis proper as I have more interviews to do, but I find I am getting a real sense of the common themes and feel of the interviews.

May 11th. Did an interview today that seemed quite different to the others. The respondent was very matter of fact and pessimistic about the client, giving quite a limited description. The interview revealed her deep dissatisfaction with where she works, around management and staff and what she sees as abuse of clients' rights. She gets little satisfaction from her job now and feels clients are deteriorating. It made me wonder whether the sense of emotional connection that seems to enhance staff views of clients also needs to be a sense of connection with the wider system, the staff group and the organisation. Perhaps alienation from this alienates one from the client as well.

May 15th, Did three interviews last week. They all seemed to go well. Most respondents seem to take the questions and run with them, needing minimal encouragement and probing from me, which is encouraging. I find I am getting better at relaxing and following their leads, rather than obsessively following my question format, although I still worry, being a novice, about covering the areas I have outlined for myself. Having experienced the setting up of the research as a fairly nightmarish experience, I am pleased to find that I am still interested in the subject and my head is buzzing with all sorts of themes and connections. The overriding feel I get from the interviews so far is the importance of emotional connection with the clients and how this facet can change perceptions.

Tony has suggested I might use IPA instead of grounded theory. This arose after I said that reading transcripts, higher order categories seemed to jump out at me. Tony said that the IPA process for reaching these categories was more straight forward than grounded theory and might suit me better as I tend to perceive the categories quickly. Also, what I am looking at is very much the phenomenology of personal experience, highly suitable for IPA, so I think I will go with it.

May 20th. An interview I did yesterday clearly brought into focus a point, or rather a process I had not been fully aware of before. In this particular interview the respondent really seemed to struggle with her perception of the client, trying to locate him either in normal or abnormal space. This has happened in other interviews but what seemed more explicit here was the way she poignantly described her first impressions of him as so different to normal, so vulnerable and helpless and then went on to describe a process of getting to know him as a person, her view then becoming more positive and rounded, a view which then has to be defended. Looking back over my other interviews now, I am struck by the respondents early expectations/ feelings about this client group; fear, pity, shock, hopelessness, sadness; feelings which later they all too clearly see in others. The process they go through locates themselves with the client against these views but the tension always seems to be there.

June 8th. Meeting with my supervisor. She feels my introduction is basically fine but agrees with me that I need to add a bit about interpersonal relationships, need for reciprocity and equity etc. We also discussed the fact that my self-selected sample seem to represent a certain subset of care workers in a particular geographical district, articulate, committed and who work for statutory and voluntary services that stress having positive attitudes towards the clients. None of my respondents work in the private sector which, in my supervisors experience have more care staff with traditional attitudes, akin to the 'provider' stance of meeting physical needs or beyond this, even abusive attitudes and practices, with very different language used to describe and talk to clients.

Also met with Sue Holttum today. I brought up the fact that a lot of my themes seemed to be in dichotomies within interviews, e.g. client described as same as normal at times, other times as very different to normal. Sue said this was very similar to some work that was done looking at racial prejudice and people's descriptions of minority groups, so I will have a look at that. Also discussed problems surrounding respondent validation. I am getting the impression that the conflicts that seem to be portrayed in the interviews are at least partly not fully conscious. Respondents may not recognise, or feel comfortable recognising the themes that are emerging. This means they may not validate them and also may find it threatening or distressing. Sue says this may be a good reason for not attempting respondent validation but I will have to decide.

Writing up my results, it still seems quite unclear at times which makes me wonder, should I keep going back over the interviews. I think I should. The problem seems to be that many of the themes overlap. I am writing a quote to illustrate one theme and it reminds me of another. It could be that I haven't been rigorous enough in sorting my themes and perhaps I am making one theme into two or more. Or maybe it is a good sign and means my themes are coherent, fit together, impact on each other and tell a story, which after all is the whole point of the process. For example, the theme of knowing/ not knowing and the theme of whole person/ part person seem to interconnect. This isn't surprising as a key factor of knowing is to do with how much you feel you know about the person. However, I don't feel they are the same theme as the whole person theme is much more about the 'personhood' of the client as opposed to just amount of knowledge, so I feel there is a qualitative difference. Perhaps the important thing is to flag up when this interconnection happens to show I am aware of it and also to make the whole thing fit together better for the reader.

June 20th Continuing with my results, I was describing the theme of locating self with the client, which has now struck me as a very crucial one and perhaps at the heart of the conflicts that are apparent. Looking back at the literature on relationships and roles, it has struck me that a major difficulty for these workers is how to construe their relationship with the clients, what sort of relationship is it? For these workers anyway it is not just a job with the clients as the 'job to be done', akin to Clegg's provider' relationship. They don't want it to be parent/ child. They try to make it 'friends' but this is hard to sustain as it is so different from what one would call friendship usually. Perhaps this is true of all caring relationships, e.g, in mental health, but in profound learning disabilities, the carers seem to be trying to be so much more and the clients are so different to themselves. The huge gaps in knowledge and communication seem to create a space that is ripe for speculation and fantasy. What seems to be so hard is

to accept the person for what is apparent and still feel there is meaning in the relationship and the job. No wonder there is conflict.

July 3rd. Now into my discussion of results, the idea of the construction of personhood seems a very crucial one to me. In particular, if one accepts the intrinsic worth of all life then there is no conflict or debate about personhood. If on the other hand one accepts a gradient there is then a huge grey area and decisions to be made about where to locate certain individuals and groups on the gradient and these decisions have consequences, e.g, withdrawing feeding in persistent vegetative state or babies with severe brain damage.

Also, I feel it is important to point out in my discussion that the conflicts that are discussed are not just an issue for care staff. It becomes an issue for them because they put themselves in contact and become involved. However, it is also an issue for other professionals and for society. For example, psychologists split off parts of the person to treat. We are all uncomfortable with aspects of disability but in common with other devalued groups, the debates are very consciously and socially defined and focus on overcoming prejudice and stereotyping. Bringing the negative into the debate is very difficult.

Observation

Behaviour

Well , he has to use a wheelchair most of the time but he is able to walk or run for short distances and reach out for things that he recognises or wants and particularly on holiday, he made that very clear that he wanted to go out, by going to the door. He was able to walk to the door or grab his coat so he was able to make some of his needs known

Noises

Well, he would be very verbally angry, well being very loud and shouting

By shouting, he was very definite, if you put him in a situation he wasn't happy with.

Facial expressions

Well, a lot of it was eye contact, we'd have a lot of eye contact.....

He would often smile, or not smile as the case may be.

Knowing versus Uncertainty

Difficult to know

I've known him for about 5 years, well longer, but I've worked with him for 5 years. I think not an easy person to get to know really.

I mean he was sort of prone to being incredibly angry and it wasn't always easy to recognise why that was

... you want to try something out and he wasn't happy but it was very difficult to discern until you did it, that he wanted to do it or not.

Often as not he would go to his room and just be really angry, shouting and everything and sometimes we knew what the reason was and other times it was very difficult to recognise what it was.

History

I think you need to know an awful lot of background

Knowing

_I think the best way I got to know him was by going on holidays with him, I went on three or four holidays with him over the time I knew him and that's always a great experience because you can just focus on one that person, you're not in the group

home with all the other issues, all the other people living there, and you really get to know his rhythms

But it takes a lot of time, it took me a long time to feel I did know him, but it was always through doing things, activities. You couldn't tell it from him just by meeting him because obviously he wasn't able to talk to you, so it was very much a long term thing.

Speculation

It's frustrating not being able to know, you feel you're only scratching the surface really.

Normal versus not normal

Same as normal...

and I still remember those experiences and shudder. But time passes and you can forgive those things like you can to a lot of people who maybe put you through bad experiences.

Different to normal:

Yeah and that's difficult, because sometimes you're trying so hard to treat someone as you would anyone else but then you have to pull back because that person has a learning difficulty

And I've also become a lot more aware of the situations I've put people in, because you're trying your best to offer new opportunities and experiences to people but sometimes they're just not ready for them and maybe will never be ready for them

But I think if you're working with people that are very egotistical, very self centred, not generally the sort of people that in my own social life I would have anything to do with at all

Better than normal

Absolutely, and make sure they have really nice clothes, you know, often dressed a lot better than the people that are caring for them. So, you know, walking around looking really shabby and you're helping someone around that has a brand new leather jacket on. You feel in some ways your letting *them* down.....

Emotional Connection versus Detachment

Connection with families

fortunately his parents and his immediate family really value him and I think that and I think that really help you to understand him a bit more and just seeing that he's needed makes you feel you're part of something. It helps you connect with them a bit more..

Recognition

But I don't think he really recognised me until about a year, he only smiled at me after about a year, that's the first time he smiled at me.

I think the first time he smiled at me was quite a major thing for me, because it just seemed to be a smile of recognition. Maybe I was reading that into it but it had never happened before and this was nearly a year. So that was quite a major thing and it really meant a lot to me.

Suddenly this person smiles at you when you say hello in the morning and it seems like a major thing..

Shared experience

.But sometimes you can really go with it and really enjoy it with him and it was like a shared experience

Warmth

I think although rather than just being this person I had to work with and had to help, you know, physically help and do things to him, just physical maintainance, suddenly you warmed to him in a more personal way...

Own worlds

The first group of people I was supporting were really difficult people to be with and very much into their own worlds and it's very difficult to connect with

....sometimes you meet people that seem to be very quiet or so involved in their own world, it's difficult to deal with someone that doesn't seem to project themselves at all, that's something else altogether.

Lack of reciprocity

sometimes it's having to put so much effort and not getting immediate results and getting very little feedback or gratitude I suppose.

Negative perceptions versus positive perceptions

Positive perception of client

Well, there was one time when we took him on an outward bound course and we actually tried doing some rock climbing with him which I really wasn't confident about. He ended up climbing nearly thirty foot up this, not a sheer face, but was quite difficult, and he did it on his own, I mean he had ropes and he was being helped but he did it completely on his own. It was astonishing to see and I was scared to death, I was so impressed with him and he seemed to be quite pleased with himself as well.

_I suppose, I mean you got this feeling when you were introduced to him that everyone really liked him, he was a good looking lad as well, I suppose that's one thing that's in his favour. Some people I've helped haven't been... attractive or the way they verbalise or whatever makes it very difficult... immediately puts people off and it takes that extra effort to feel comfortable sitting with someone or whatever.

I remember going on a train with him for the first time and it was always surprising what he was able to do, even if it was really difficult physically for him, he would really try. I think you would start to admire that in him.

Positive perception of difficult behaviour

_sometime he was being a bit outrageous but there were ways of avoiding that or calming him down but most of the time I really enjoyed it. People would look at us because he would be quite loud, laughing but I was laughing as well because I was having a good time with him and I never felt embarrassed by him..... I think sometimes people feel quite tense when their out with people but I got to the point when I enjoyed his behaviour even though it was a bit outrageous.

Negative perceptions of clients

that was a very difficult time as well, being in an environment where there was a lot of disturbed behaviours and a lot of destruction going on around you for no apparent reason.

It's funny really, because the people that at this time I was working with, I was aware of the other groups of people that I ended up supporting, and at the time I thought, although I was working with people with very severe behavioural difficulties, I thought I would much rather do that than work with people with very severe physical disabilities. I couldn't imagine doing it but through circumstances I ended up working with that client group and there were aspects of it that were very difficult

There were lots of things I hated. I hated being out in town and I used to get incredibly embarrassed by incidents, you know, in a supermarket or café, people doing the most outrageous things, it used to really crush me sometimes..... and it would make you really embarrassed and really angry

_That was always difficult because you couldn't get close to him to help him because you couldn't talk to him and because he was so angry that you couldn't calm him down. That sometimes made it very difficult to be around him

And it's always difficult if you're working with people who self injure, it's very upsetting to see.

I get angry and frustrated when people let themselves down, maybe they don't realise what they're doing but when you're out in general public, if you start attracting a lot of attention to yourself, it's embarrassing for me but I also get really upset because that person is creating a bad impression of themselves.

Perception of clients damaged:

I was on holiday with one guy and when we got back I was so exhausted and he kind of really rubbed our noses in it...we'd tried so hard. I could barely talk to him for about two months. It was very difficult and it was very damaging

Negative perceptions by public:

I think a lot of people still have very traditional views...I think it's still quite negative unfortunately or ...there are still people who don't have that much contact and I think people are still quite fearful of seeing people that are in wheelchairs and obviously have really profound learning disabilities

Whole person versus not a person or part person

Part person/ whole person:

I think sometimes I got so wrapped up in that, as you do, making sure he was physically well, rather than looking at him as a whole person.

Non person

I mean, I was introduced to various people that lived on this ward by what was wrong with them, often as not their names came last.

Client as a child versus as an adult

Parents seeing client as child

Well, sometimes it's difficult because they still can be quite...still treat them like children which is always difficult when you're trying to project that person as a young man or a young woman and they come in and really sort of play with them or whatever. It's hard. You have to sort of stand back and appreciate them that their experiences are so different from yours because you are working in a professional capacity and they are their children.

Sympathy with family view

Yes, or well, accept the fact that you can't understand what it's like to have a child, well, a young adult child, that's all grown up but never got better....I find that very difficult to get to grips with sometimes, I just have to stand back and accept that I'll never really know what that experience was like.

Conflict with family view

Yeah, absolutely, that's right and sometimes it wipes out everything you've been trying to do with that person, when you realise that their family perceive them in such a different way.

Influence of staff, teams, philosophy

Negative staff attitudes

I really didn't know and when I got there I was quite horrified but not by the people that lived there but by the staff and their attitudes.

I think the only thing that kept me going was I knew this place was closing and better things were going to happen which they did. People were moving out to group homes so I knew that was on the horizon, I think that's what kept me going because the place itself was awful and the way the people were treated was something... I could already see that that wasn't the way to be treating people... not the way I would ever treat people, physically or mentally.....

Positive team

Yeah, definitely, I think it was a big learning curve and I think it was a very special time for me. I was learning a lot more about working as part of a team and that helped me a lot.

Ideals versus reality

I don't know, I mean... being part of an original project to get people into the community whatever their abilities were.... I mean, initially were quite evangelical about it and thought we were really making a big difference, and that everyone would notice that these people were part of their community

Locating with clients

Client as friend

When I used to walk in town with him, I just felt like I was out with a mate, going out on a Saturday.

Power difference

as I said before I never got used to, doing actual physical care to people, I just never liked having that kind of power over people, although it had to be done

Well, I suppose it's exerting your power over people in a different way which was equally difficult because you had to be very direct with people and that's not really in my nature—to be going round ordering people around, making people do things but that was the way you had to work around certain things.

Interview Transcript - Freddy

This is about a man in his mid thirties who has profound learning difficulties and physical difficulties so he needs a lot of support. I've known him for about 5 years, well longer, but I've worked with him for 5 years. I think not an easy person to get to know really. I think you need to know an awful lot of background but fortunately his parents and his immediate family really value him and I think that and I think that really help you to understand him a bit more and just seeing that he's needed makes you feel you're part of something. It helps you connect with them a bit more, even if it's just sort of information that you know about him. I think the best way I got to know him was by going on holidays with him, I went on three or four holidays with him over the time I knew him and that's always a great experience because you can just focus on one that person, you're not in the group home with all the other issues, all the other people living there, and you really get to know his rhythms, when his tired, when he really wants to go out and do things. But I don't think he really recognised me until about a year, he only smiled at me after about a year, that's the first time he smiled at me. I think that maybe to do with... I was a man because he responds a lot more to women and.... Yeah, I think women workers maybe have a very different relationship with him in some respects. I think mine was maybe a lot more physical with him because I used to do a lot more outdoor things; go for walks, go on trains, do outward bound things, we did rock climbing. So we always used to go out a lot and that could be quite exciting and a bit dangerous sometimes because he would tend to reach out in town, quite gregarious and very loud which sometimes was slightly embarrassing. But sometimes you can really go with it and really enjoy it with him and it was like a shared experience, sort of, he was a bit of an anarchist really.

Is gregarious one of the things you have put about him?

Yeah, and adventurous and generally happy. I mean he was sort of prone to being incredibly angry and it wasn't always easy to recognise why that was. That was always difficult because you couldn't get close to him to help him because you couldn't talk to him and because he was so angry that you couldn't calm him down. That sometimes made it very difficult to be around him. Even if he needed help you couldn't really get near him.

When you say he was gregarious, how did you come to know that about him?

Well, I think it was through actually going out with him, It's not something..I mean you don't just see it in him. But once I had a few experiences of going out with him, particularly of going on holidays, you realised how keen he was.. how much he

seemed to enjoy being on holidays and really wants to go out and do things.

How did you know that about him, that he wants to go out, what does he do to let you know?

Well, he has to use a wheelchair most of the time but he is able to walk or run for short distances and reach out for things that he recognises or wants and particularly on holiday, he made that very clear that he wanted to go out, by going to the door. He was able to walk to the door or grab his coat so he was able to make some of his needs known. He was always keen to do that and when we were on holiday we were able to provide that as soon as he wanted it which was great. It was something that was obviously very frustrating when in his group home, not always being able to provide that for him and sometimes he'd get really angry about that which was quite understandable.

How did you know when he was angry?

Well, he would be very verbally angry, well being very loud and shouting or would rarely used to physically grab people. Often as not he would go to his room and just be really angry, shouting and everything and sometimes we knew what the reason was and other times it was very difficult to recognise what it was. I think of all the things we did—I remember going on a train with him for the first time and it was always surprising what he was able to do and what he was determined to do, even if it was really difficult physically for him, he would really try. I think you would start to admire that in him, that he was really reaching out and trying to do things, not necessarily things that you always provided for him, he did try other things you hadn't expected.

What sorts of things?

Well, there was one time when we took him on an outward bound course and we actually tried doing some rock climbing with him which I really wasn't confident about. He ended up climbing nearly thirty foot up this, not a sheer face, but was quite difficult, and he did it on his own, I mean he had ropes and he was being helped but he did it completely on his own. It was astonishing to see and I was scared to death, I was so impressed with him and he seemed to be quite pleased with himself as well. But it takes a lot time, it took me a long time to feel I did know him, but it was always through doing things, activities. You couldn't tell it from him just by meeting him because obviously he wasn't able to talk to you, so it was very much a long term thing. I think I probably had a much better view of him... I was still learning about him when I left. I didn't feel that I knew everything about him, not that you can, but sometimes people feel they've reached a full stop as to how much they can learn about someone and a lot of it just becomes repetitive. But I always found it really interesting being with him.

Is there anything else you've put about him?

I think that's about it really. I think the sort of relationship we had was a very active one, very physical, all about doing things.

Can you tell me what your first impression was of him when you met and how that changed over time?

I suppose, I mean you got this feeling when you were introduced to him that everyone really liked him, he was a good looking lad as well, I suppose that's one thing that's in his favour. Some people I've helped haven't been... attractive or the way they verbalise or whatever makes it very difficult... immediately puts people off and it takes that extra effort to feel comfortable sitting with someone or whatever. I think the first time I met him he was charging around the garden and that was great to see and I thought he seemed to be having a really good time.

It sound like he came across to you as an appealing sort of person?

Yeah, he definitely came over that way and he was laughing and I think that....sometimes you meet people that seem to be very quiet or so involved in their own world, it's difficult to deal with someone that doesn't seem to project themselves at all, that's something else altogether.

I was wondering if there were any specific situations or events that impacted on how you saw him... you already mentioned going away with him as quite important. Were there any other examples of how your view of him changed?

I think the first time he smiled at me was quite a major thing for me, because it just seemed to be a smile of recognition. Maybe I was reading that into it but it had never happened before and this was nearly a year. So that was quite a major thing and it really meant a lot to me.

Do you think it actually changed your view of him?

I think although rather than just being this person I had to work with and had to help, you know, physically help and do things to him, just physical maintenance, suddenly you warmed to him in a more personal way...

Like a connection.?

Yeah, it just felt like that but it took a good part of a year for that to happen.

Were you aware of a gradual getting to know him better over that time?

Well, only on the day to day. I mean, obviously, I became more aware of his physical needs but a lot of it was ore of a routine, day to day. I think sometimes I got so wrapped up in that, as you do, making sure he was physically well, rather than looking at him as a whole person. Suddenly this person smiles at you when you say hello in the morning and it seems like a major thing, particularly seeing he had relationships and recognised other people and you felt a bit left out really or wondering what you were doing wrong, but obviously he doesn't have to like everyone. I suppose it's quite difficult because you're with someone all that time and you expect him to like you but.....But I think after being on these holidays, they were definitely major events for me. We did some wild things, cross country hiking, over stiles.

You said it was because you didn't have other distractions you were able to concentrate on him, but do you think he behaved differently as well?

Oh yeah, he definitely knew it was his holiday and we were there for him. He was just really different and that was great to see because you get so wrapped up with the day to day and having to think about not just him but all the other people in the house. When I used to walk in town with him, I just felt like I was out with a mate, going out on a Saturday. I never had this feeling I was out with this person in a wheelchair. O.K, sometime he was being a bit outrageous but there were ways of avoiding that or calming him down but most of the time I really enjoyed it. People would look at us because he would be quite loud, laughing but I was laughing as well because I was having a good time with him and I never felt embarrassed by him..... I think sometimes people feel quite tense when their out with people but I got to the point when I enjoyed his behaviour even though it was a bit outrageous.

Did your view of him which changed on holiday continue when you got back?

Yeah, it definitely built up to another level and it's difficult to maintain that when you are back in the day to day, but it's certainly someone I feel is quite special to me and someone that I still think about.

Can you tell me a bit about how you and he communicated with each other, he with you and you with him.

Well, a lot of it was eye contact, we'd have a lot of eye contact..... And he would always be reaching out for the things that he wanted. Some days he was better than others. Some days he wouldn't really let people know what he wanted... but certainly you used to get a lot of eye contact which really helped, you felt that he...although he couldn't talk to me, I felt that he was looking at me and responding to my voice.

How would his feelings show?

He would often smile, or not smile, as the case may be. There were plenty of time I probably really brassed him off as well, just by maybe offering things at the wrong time, or not recognising he was tired and sometimes we would have quite a difficult day and he would get quite angry with me but we had to step back from that.

And how did he show that anger?

By shouting.. he was very definite , if you put him in a situation he wasn't happy with, you know, for the best reasons, you want to try something out and he wasn't happy but it was very difficult to discern until you did it, that he wanted to do it or not.

What about behaviour.. ?

Yeah, physically he would get quite wild with his arms and very loud or sometimes he would just withdraw into himself and get very quiet and sullen. Just close down You just couldn't explain to him what you were going to do in advance.

How did you communicate with him, your intentions or feelings?

Well, sometimes it would have to be very immediate, like if we were going out in the car we'd show him the car keys or, he also used to go horse riding and he had his riding clothes and he definitely associated those with that, so it had to be very physical, very visual things. But very difficult to explain anything which was a bit more subtle.

What about verbal communication.?

Oh yeah, I used that all the time, all the time speak to him, I mean you have to and as much eye contact as possible.

How do you think he sees the world?

As his, I suppose. I think on the whole it's quite self centred which is not necessarily his fault but... I don't know, sometimes I think with his immediate family, he's great with his nephews and seems to be very gentle with them which again is a real surprise to see him with them and how... I mean, they were great with him and just treated him like an uncle but.. he was surprisingly gentle which I'd never seen before, so he definitely responds to different people or knows different people do different things like he always used to get up when I came in and head for the door because we were going out so I think I was one of his visual prompts in a sense.

So you're saying he responded to the bits that affected him?

Yeah, he was very much, yeah, I mean he didn't seem to have any relationship with the people that lived with him in the house. They just seemed to get in his way, physically and he always went to staff for what he wanted. Since he moved to his new house there's a lot more opportunity for him to walk around and he really does use space a lot more.....

So he's widening his horizons?

Absolutely and he really does that which is great to see. He had very limited access in his old house and now he's really chasing about and can freely get in and out of his bedroom.

What do you not know about him?

There is still an awful lot I don't know about him because it's all about my experiences with him, like I say, all about doing things but sort of spiritually, it's very difficult to know how maybe he feels or what... I've no idea what his real feelings are toward particular people. It's frustrating not being able to know, you feel you're only scratching the surface really.

So you feel there's a lot under the surface...?

Or I would like to think. I mean, you can imagine or hope for maybe a lot more but sometimes that's maybe not the right way to think about people because you're not accepting people for how they are. I mean, your kind of wanting more to fill the gaps in. I used to have lots of dreams about him when I was talking to him, I think it's just a need that people have to fill in the gaps..

Sounds like what you're saying is there may be lots of stuff you don't know about him but you realise part of that is maybe you hoping...

Yeah, I mean in some ways it's not necessarily a bad thing but sometimes you're maybe trying to compensate for that person's disabilities and not accepting them, subconsciously not accepting, finding it difficult to accept how difficult that person's life can be sometimes and how vulnerable a person is, you know. I do find it very difficult, aspects of helping are very difficult because he was so vulnerable and that having to use certain apparatus like lifting hoists, and I've always found that difficult. I've never got used to that and in some ways I'm pleased that I haven't, you know, become blasé to physically moving people around.

Can you talk about your experiences generally working with this client group and how those experiences affected the way you see the work and the clients?

When I first started this work I had no idea of what I was walking into and also, kind of changes your relationship sometimes, when suddenly you're physically in control of somebody, because it was at an institute (*sic*) I had very little idea, I don't think I had ever met anybody with a profound learning disability before and I was already 22 or 23.

So what were your expectations?

I really didn't know and when I got there I was quite horrified but not by the people that lived there but by the staff and their attitudes. I mean, I was introduced to various people that lived on this ward by what was wrong with them, often as not their names came last.

And even then, without any experience that struck you as.....

Yes, it just seems a bizarre way of introducing someone, by saying what was wrong with someone, they didn't even say their name.

What brought you to the work in the first place?

Well, it was a job. It didn't start off as a 'I desperately want to work with....'. I had no expectations at all and they were nearly completely wiped out when I first went there. I think the only thing that kept me going was I knew this place was closing and better things were going to happen which they did. People were moving out to group homes so I knew that was on the horizon, I think that's what kept me going because the place itself was awful and the way the people were treated was something...I

could already see that that wasn't the way to be treating people... not the way I would ever treat people, physically or mentally.....

But after that.....

Yeah, definitely, I think it was a big learning curve and I think it was a very special time for me. I was learning a lot more about working as part of a team and that helped me a lot. The first group of people I was supporting were really difficult people to be with and very much into their own worlds and it's very difficult to connect with and then I moved on to working with a group of people who were very challenging, behaviour wise as well but I stuck at that and that was a very difficult time as well, being in an environment where there was a lot of disturbed behaviours and a lot of destruction going on around you for no apparent reason.

In general, how do think your experiences shaped your views and the way you work?

It's funny really, because the people that at this time I was working with, I was aware of the other groups of people that I ended up supporting, and at the time I thought, although I was working with people with very severe behavioural difficulties, I thought I would much rather do that than work with people with very severe physical disabilities. I couldn't imagine doing it but through circumstances I ended up working with that client group and there were aspects of it that were very difficult like, as I said before I never got used to, doing actual physical care to people, I just never liked having that kind of power over people, although it had to be done.

So it's more difficult than challenging behaviour for you?

Well, I suppose it's exerting your power over people in a different way which was equally difficult because you had to be very direct with people and that's not really in my nature—to be going round ordering people around, making people do things but that was the way you had to work around certain things.

How do you think your work experiences impacted on your attitudes towards the work and the people?

There were lots of things I hated. I hated being out in town and I used to get incredibly embarrassed by incidents, you know, in a supermarket or café, people doing the most outrageous things, it used to really crush me sometimes..... and it would make you really embarrassed and really angry at that person even if they weren't aware of what they were really doing. I mean, sometimes people did seem to know what they were doing and knew they were making a big impact on their environment and sometimes you would get really angry. You'd try your best to understand but sometimes even with all the backup and support you could end up really hating someone for putting you in that situation. Just think 'how could you do this to me?'

Like just a human reaction really....

Well yeah, that's the problem, you spend so much time trying to adapt your behaviour and trying to be so aware of the environments you're putting people in, preparing for

doing things and then that person throws it back in your face or...it can really knock you back. I was on holiday with one guy and when we got back I was so exhausted and he kind of really rubbed our noses in it...we'd tried so hard. I could barely talk to him for about two months. It was very difficult and it was very damaging although I see him now, he's one of the few people that seem to recognise me from that group of people and I see him now and I still remember those experiences and shudder. But time passes and you can forgive those things like you can to a lot of people who maybe put you through bad experiences.

But in general, how do you feel about the work you do.

I still feel, after about 14 years, I'm applying for another job in a group home, which surprises me in some ways but I've actually found another group of people who I really like, because I wasn't sure if I could do that, but I have and I feel energised again and keen to....I've spent the last 3 years working in lots of different places on the agency and I really didn't know if I could commit myself to another group of people and involve myself in their lives again.

So what is it that motivates you?

I don't know, maybe..it's very difficult to put your finger on it but, this particular client group.. I like it because they are very keen to go out and do things which I can relate to. I find it incredibly difficult to be in with people all the time, not keen to go out because I get very claustrophobic stuck indoors all the time so I like to be with a group of people who are very physical.....

So that's one of the best things about the job for you... being active...

Yeah, and this group of people are not all...I mean some people are able to speak which is quite unusual in my past experiences.

Why do you think that is, why you haven't for maybe worked with people with mild learning disabilities?

It's just opportunities, I think. I don't think I've avoided particular groups. But I have stuck with groups of people for 3 or 4 years at a time, if not longer. I don't think I've actively chosen not to work with certain groups of people, although now I don't think I could work with people with really challenging behaviour, physically challenging, not towards me anyway. And it's always difficult if you're working with people who self injure, it's very upsetting to see.

I was going to ask what sorts of things you found difficult about the work...you've mentioned challenging behaviour and self injury... are there other aspects of the work you don't enjoy?

I suppose..... sometimes the repetition, sometimes it's having to put so much effort and not getting immediate results and getting very little feedback or gratitude I suppose.

Do you mean from the clients?

Yeah, sometimes it would be really nice for someone to say 'thank you' in whatever way someone could, even if not able to speak, get something. But I think if you're working with people that are very egotistical, very self centred, not generally the sort of people that in my own social life I would have anything to do with at all, but I find myself supporting people who are completely involved in their own lives.....

So having to have different rules for people?

Yeah and that's difficult, because sometimes you're trying so hard to treat someone as you would anyone else but then you have to pull back because that person has a learning difficulty and you can't criticise someone for being selfish although sometimes you'd love to and say 'what about me?' and that doesn't wash and that can be very frustrating... And I still get embarrassed sometimes. I think my embarrassment threshold is not as high as it used to be. But I don't like to see people... I get angry and frustrated when people let themselves down, maybe they don't realise what they're doing but when you're out in general public, if you start attracting a lot of attention to yourself, it's embarrassing for me but I also get really upset because that person is creating a bad impression of themselves. It does really wind you up for loads of different reasons which are always difficult and always present.

In general, how do you think other people see the client's you work with?

I don't know, I mean... being part of an original project to get people into the community whatever their abilities were.... I mean, initially were quite evangelical about it and thought we were really making a big difference, and that everyone would notice that these people were part of their community. But I think I've become a lot more pragmatic over the years and a bit more, I suppose, cynical as well, that maybe in some respects we've come as far as we can.

So what do you think other people make of the clients?

I think a lot of people still have very traditional views.... I think it's still quite negative unfortunately or ...there are still people who don't have that much contact and I think people are still quite fearful of seeing people that are in wheelchairs and obviously have really profound learning disabilities. I think all you can do is try your best to project that person as well as possible, at least show people that you really value them.

How do you feel about those views?

It's still very difficult. I mean, I used to be a lot more aggressive with people when they did say.. when they were negative to me if I was out with a client but then I realised I wasn't doing them any favours either, getting thrown out pubs, well, not even being allowed in pubs for instance or café's. At one time I would have had a stand up fight in front of..... which made it even worse, and I did learn to cool that

down. We'd just leave and I'd go back after I finished my shift and have argument with them or have a word with them.

But it still makes you angry, you just handle it differently?

Of course, yeah, I've learned to not be so evangelical about it. I think we were all initially very fired up and we made an awful lot of mistakes as well, you know, I think I've become a lot more sympathetic to the general public, definitely....because it's all very well creating opportunities for people and saying people can go to restaurants or the cinema, all these kind of things which are supposed to be valued pursuits, but if that person isn't enjoying it or behaves in a way that upsets other people, at one time I wouldn't be that aware but I think now.....

What do you think led to your views shifting?

I don't know, I think it took a period of time, just me becoming more aware of the more and more difficult situations that arose taking people out and seeing the responses from people in those places. Instead of becoming angry, I became more sympathetic, O.K, I've spent 15 years around people with learning difficulties but they haven't, and won't have to. It's terribly difficult for people to deal with. And I've also become a lot more aware of the situations I've put people in, because you're trying your best to offer new opportunities and experiences to people but sometimes they're just not ready for them and maybe will never be ready for them. I mean, not everyone likes doing some of these activities, like going to a restaurant. You need an awful lot of information to enjoy those experiences, and if you've got someone who is just hungry, they're not really, in my experience, sometimes people are just not interested in all the different foods on the menu.

It sounds like what you were saying before, you were evangelical but now you focus on the person as an individual, will they as an individual get something out of it, rather than, 'it's our job'.....

Yeah, like 'we have to do this' and everyone is going to have to cope with it. I think I've become a lot more aware of the impact you can create. I still get a lot out of it and it's difficult to put my finger on sometimes because, you know, a lot of people never talk about it and they could have been doing it for 10, 12, 15 years but they never address why they're still doing it and what they get from it. I mean, I think some people do it for equally selfish reasons. Sometimes people will want to be seen as good people and I'm not sure sometimes, maybe sometimes I feel like that.....

That it gives you a sense of self worth?

Yes, but I don't want people to look at me when I'm walking round town with someone using a wheelchair saying 'oh look at that person, he's...' and you do get that, you get a lot of people saying 'I couldn't do that, you must be so patient' and I'm not. I think it requires a lot of application but I don't think I've got any more patience than the next person.

Moving on to people's families, in general, how do you think client's families see them?

Well , in my experience, I've been lucky because a lot of people have good family connections around them. There are not many people I've supported who have no connection with their family and a good connection, that's always been very useful..

And how did those families view the clients?

Well, sometimes it's difficult because they still can be quite... still treat them like children which is always difficult when you're trying to project that person as a young man or a young woman and they come in and really sort of play with them or whatever. It's hard. You have to sort of stand back and appreciate them that their experiences are so different from yours because you are working in a professional capacity and they are their children. For better or worse, you can't start lecturing people about how they treat their children.....

So it feels uncomfortable but you do understand why they see them like that?

Yes, or well, accept the fact that you can't understand what it's like to have a child, well, a young adult child, that's all grown up but never got better... I find that very difficult to get to grips with sometimes, I just have to stand back and accept that I'll never really know what that experience was like.

A different world completely from your relationship with the client....

Yeah, absolutely, that's right and sometimes it wipes out everything you've been trying to do with that person, when you realise that their family perceive them in such a different way. But then again sometimes, I've worked with people who seemed to have taken their sons or daughters completely on board and really involve them in their lives, which is really encouraging.

Treat the more like an adult...?

Absolutely, and make sure they have really nice clothes, you know, often dressed a lot better than the people that are caring for them. So, you know, walking around looking really shabby and you're helping someone around that has a brand new leather jacket on. You feel in some ways your letting *them* down (*laughs loudly*)

You sound as if you quite like that in some ways, maybe redressing the balance?

Absolutely, like everyone's going ' look at this smartly dressed guy with that tramp pushing him around'.

Finally, I'm interested in how you think the clients are viewed by professionals they may have contact with...if you've got experience of accompanying clients when they see nurses, doctors, social workers, psychologists, psychiatrists, occupational therapists, speech therapists, physiotherapists.

Well, I suppose I've has some quite negative experiences as far as that's concerned, particularly with G.P's.... I think that's been the worst really. Just the lack of interest

really, and really having to force that interest out of them to get something done when you know the client is really not well or needs some help.

So they don't view the client as worthy of help?

No, not at all. That's happened a lot.

Why do you think that is?

Maybe it's...mind you G.P's are famous for that with all patients so.....but it's been very difficult and sometimes even at the point of contact, we had an awful time once with a G.P's receptionist trying to diagnose the person, like 'why do you need to talk to the G.P', you know, had a very arrogant view. It makes me feel really angry, and resentful that we're really not getting great value, not getting things done properly. But it's not all the time. I mean I've had some very good experiences with speech therapists and years back we had a really good clinical psychologist who was incredibly supportive.

What was positive about their views of the clients?

Just because they had a really good attitude and it seemed to depend on which one's you came across really...

What were their attitudes?

Just very positive, very enabling, very supportive to the staff that were helping them. They made you feel that you actually did know something about that person and it helped you so much more in helping that person.

What about their views of the clients?

These particular people were excellent, very enabling.

That's it, thank you very much, how did you find it?

Yeah, very interesting..you know to think about the work in such detail, like I said you don't often go through why you do it so it was good.

How about the questions?

Yeah, they really got me talking, very open, yeah, good.

Respondent- Andrew

1

The client appears very withdrawn at times, often staying in bed for days at a time.

2

Communication seems contradictory; one of the main problems is in establishing yes/ or no, like or dislike as to ordinary questions, e.g, ‘would you like to go out’ or ‘do you want to eat’.

3

At better times the client comes across as having a terrific sense of humour, an artistic

4

5

sensitive personality and a great lover of music.

6

So there is on one hand a sense of being confounded by a withdrawn person’s

7

behaviour, on the other hand a sense of being with a person who can really enjoy their world.

Categories

Behaviour	1 and 6
Communication	2
Personality traits	3 and 4
Likes/ dislikes	5
Abilities	7

Themes

In the first part of the interview, participants talked about a description they had written about a client. This focused on finding out how they had got to know things about the clients, such as likes and dislikes, feelings, needs and wants. This all amounted to fairly practical care staff observation of the following;

Facial expressions

Body language

Noises and sounds.

Other behaviour

Therefore, theme 1 is observation of any of the above.

As the interview developed, more complex themes developed that show processes that impact on care staff perceptions of clients. Some of these were in the form of dichotomies. Occasionally these dichotomies were expressed consciously by a respondent but more often different poles of the dichotomy were expressed in different parts of the interview.

2 Knowing the client versus not knowing.

This is about respondents sometimes feeling they know the client, at least better than others do, but despite all the observation of the factors mentioned above, still not knowing fully about the client. The theme also covers respondents perceptions that others do not know the client. Respondents also speculate about what they don't know of clients and imagine what might be going on inside or what might have been.

3. Normal or better than normal versus not normal

This theme involves respondents sometimes describing clients as the same as or even superior. to 'normal' people, at other times describing them as very different. This might be around appearance, understanding, abilities, relationships. The theme also includes questioning normality itself.

4. Emotional Connection with clients versus feeling of detachment

This theme is about respondents needing and enjoying a sense of connection with clients. This includes feeling the client recognises the respondent, a sense of reciprocity, acceptance and also shared experiences. The opposite is feeling the client does not know the respondent and is in their own world or not concerned with the respondent.

5. Negative perceptions of and feelings about clients versus positive feelings.

These include fear, pity, shock, distress, seeing the client as vulnerable, sad, dangerous, hopeless, pointless, etc. These are commonly perceived by respondents

in the reactions of others, but respondents also describe some of these feelings in their own perceptions at times, past and present, and some describe their perceptions of clients being damaged by negative experiences. These perceptions are contrasted with the perception of positive qualities in the client.

6. Seeing client as child versus seeing as adult

Again, commonly perceived in others but also occurs in respondents descriptions

7. Seeing client as a person versus not a person or parts of the person

The opposite of seeing the client as a person is just seeing them as disabled, not an individual. The part person bit refers to others, particularly outside professionals, only seeing and dealing with particular aspects of the client, not the whole person.

8. Respondents Locating self with the client.

_This involves respondents talking of clients as friends, identifying with clients by using language such as the word 'us' when talking about clients. At a less identified level it involves respondents advocating for the client, feeling they have to talk for and explain the client to others. This perception is challenged by perceiving power differences between clients and staff.

9. Influence of colleagues, teams and care philosophy

This is about the affect of the above on how the respondent views the clients and the work. It is about respondents perceiving the positive influences of being in certain teams, being influenced by seeing how others work, and the role of normalisation. It also covers the influence of seeing 'bad' staff practice and attitudes, and the questioning of normalisation.

1. Basically, we don't know what a human being is, that's a pretty core belief with me, so what I mean is from what little I've read of psychology, there's a large unaccountable element for how a person actually is and you can attribute that to all sorts of factors, their background, their peers, experience, education. But how does a person structure their world, what is their vocabulary of experience, where does that come from? So in that sense I see us as all equal and unable to make presumptions about anybody although we do all the time.

2. Today, after we'd been walking for about 20 minutes, he put his arm through mine and started singing- well he sings—it's normally a very short tune—a wordless tune (*respondent hums*) and I was singing with him and we walked along for about half an hour just singing with our arms linked which was really nice. Even when we got back to the minibus and he took his arm out of mine, he then just put his hand on my shoulder which was a very nice, a very gentle sort of gesture. Really, it's nice when he comes back to us in that sort of way because he can go a very long way away.

3. But there are whole sides to him which I'm sure we don't know and it is hard to say what they are because we don't know what they are but I feel there is a quality, there's a sort of almost, sounds silly, but a mystical like, because when someone doesn't speak, just on a literal sense, I don't know how he thinks.

4. . I mean when I was very young I couldn't see the point of them being alive, that's a very fascist view but I used to think 'why don't they just get rid of them all?'

5. Oh, I wanted to explain him to them. I thought it would be nice if we could have gone there with him so they could see how he can be rather than seeing him as someone who is frightened and who made them feel anxious.

6. .. I recall one piece of work that one of the community nurses did and he had to go on the minibus, this person, because of serious problems that were happening on the bus, and it just seemed like all he's doing is he's seeing this bad, this very difficult bit of behaviour. He didn't see the other bits, like I know that that bit's bad and it was all to do with what is the appropriate way to be transporting him and quite right, we needed somebody outside to look at that to make it better. But you thought, if only he'd seen him elsewhere in other situations, he'd get a wholer picture.

7. I've known him for about 5 years, well longer, but I've worked with him for 5 years. I think not an easy person to get to know really. I think you need to know an awful lot of background.

8. I can remember when I first started, being profoundly shocked at some of the behaviours... at seeing people who having eaten their dinner, would then see some food on the floor and eat it. I was gobsmacked...

9....it takes a while to lose those preconceptions that you have about adult human behaviour and to go back to... it's pre-adult behaviour and so I can remember the first 6 months being exhausted day after day. Partly, it's because I was learning so much

all the time about people, half the people have no speech so I was learning in a way I'd never had to learn before, except obviously with your baby you learn to know that person without language but language follows on pretty quick.

10. . Communication seems contradictory, one of the main problems is in establishing a clear yes/ no, a clear like or dislike- use minimal words rather than whole sentences....

11. I think it would be useful to talk about how we work around this problem of not knowing exactly what the client wants so..

12. I think so and it doesn't have to be even verbal or body language, it's just that extra sense people have, I think.... That all people have, a sense to read situations so I think that's very strong with this client.

13. . And of course whatever set up is provided you will get those unaccountable outbursts and moodswings and they are unaccountable and will probably remain so and that's just part of the client and his life.

14. being part of an original project to get people into the community whatever their abilities were....I mean, initially we were quite evangelical about it and thought we were really making a big difference, and that everyone would notice that these people were part of their community.

15. I've not been present when the client has been in the presence of other professionals. He would have spent time with the speech therapist who I have had a talk with. There seemed to be a mix of agendas. She wanted very solid strategies such as ' offer the client the object of reference 3 times' to make sure they've understood it. Which is difficult because yes, the client has understood it and if you offer it 3 times it will end up hurled across the room.

The speech therapist didn't understand that?

I'm not sure she did.. I can't fault her for that in a sense because for her, he's just one of a caseload and the meeting might have been for a short period of time when she has met the client in a good mood.

16. One of the things he does when he is frightened or distressed is he will clench his arms to his chest, crossed over, and bang his head on the wall and he used to do that much more.

17. Yeah, that's right. Another time I was on a sleep in and I can be quite a stick in the mud about getting my sleep and I heard this client milling around and I thought she might have stopped because it went quiet for a bit. I found myself asleep and having a nightmare about the client smashing things up in the house and I woke up 2 hours later, about 4a.m and she was in the kitchen, not smashing things up actually but just tapping teaspoons and there was that horrible latency of you know, yes she could suddenly.....menace, menace is the word I'm looking for and that I found challenging in a psychological sort of way, it was nasty, it felt a bit twisted, unpleasant, that this seemed like a horror movie come true. Later on I found out, I

hadn't done a sleep in for a while, that it was policy to lock the kitchen at night if that behaviour should come up so I could have handled the situation earlier and maybe not had a nightmare and maybe that wouldn't have damaged my perception of the client so much.

18. Yeah, in the sense of when I was working with people with lots of physical disability there was this women (staff) doing a running commentary of 'what I'm doing now' and I was thinking, why is she telling this story and that's, right, that's to comfort the client because the client is actually teeth grinding, uncomfortable, knows it needs to happen but hates it. So being introduced to some really positive working teams.

19. Well, say 10 years ago I looked at someone doing a home care job and for me it was nightmarish, sort of looking after people that could never improve.....

20. He will bite his hand and grimace when he's in a bad mood. If he's very happy he'll stare a lot, he'll want eye contact and stare a lot into the person's eyes that he's with, but smiling as well, it's very warm

21. Tone of voice....when he's happy or calm, relaxed it's the same all the time. When he's anxious then he shouts, just to make himself heard really.

22. When I first met him I thought he was very detached and in a world of his own. It took a long time to get to know him actually. It took 4 years until I struck up some sort of relationship where I mean it was like a two way thing and I got some response.

23. his parents said he had half a brain and that he was like a child.

24. I do appreciate a very steady team. I would like to be able to trust everybody enough in the team to discuss the differences between team members, otherwise it does trickle down and have an affect on clients, limit or disempower them if the team is not close and mature.

25. Yeah, I mean when I first met him I thought, I'm not going to be able to cope because he looked so dependent and he is dependent, but he looked so helpless sitting there in a chair, dribbling, in spite of everyone's best efforts, looking like he wasn't really well cared for.

26. I suppose you can see where it comes from. You've given birth to somebody who apparently has not grown up into an adult.. that most people perceive as an adult in the sense of independence.

27. If he's not enjoying something he won't participate in it...would move away, hide, hide under his clothes or a blanket if there's one around, possibly become agitated if too much pressure was put on him..

28. When I used to walk in town with him, I just felt like I was out with a mate...

29. *Generally, how do families view the clients?*

As children who need everything done for them can't make their own choices, highly protective, even over protective sometimes..

30. *What about the general public, how do you think they see this client?*

Frightening, because he's got quite distinguishing features. He's very small, his physical appearance would cause them to look. Behaviours, like standing up, sitting down in a café, I think probably frightening.

31 .Through seeing the abuse like, for example, there is a T.V programme a few months ago about, you know, the thumbscrews and everything and everyone is horrified, yet only today I have seen a member of staff pull a service user to get them up to change their trousers which was frustrating the member of staff because they had to keep saying 'can you stop putting your hand down your trousers'.

32. If he liked someone, I feel he would give you a look of pleasure to see you. He'd tilt his head and look at you and give you a fantastically sunny smile and make a sort of noise when he was pleased to see you.

33. Yes, and in the noises he made so he would make either pleased to see you noises or not pleased to see you noises so you could generally tell what mood he was in by the noises he made.

34. I've also put the way that he would say to go away was either to react like that or there was another way where he would clasp his hands together and put his thumbs in his eyes to say 'just leave me alone' and put his head down.

35. He's still very childlike, I'd say in the things he likes. He likes young boys toys like cars and teddy bears.

36. Yes, as I said I was frightened when I first met him.

37. . I think the way I really got to know him was he had a gigantic rubber orange ball in his room which was like four foot high and I was balancing on it showing him I could do it too and I rolled off and fell on the floor and really hurt myself and he really laughed at me. And we spent a bit of time just rolling about and laughing and that was just a bonding moment for us.

38. . But if he was in a lively mood I think he absolutely terrified the general public. There have been occasions where he accosted members of the public and it was very much in a fun way but it could have seemed quite aggressive the public.

39... by that time I'd spent so much time around these people in this house that I knew them as people and I felt on their behalf that they were being completely ignored. I think that was the general view.

40. . But in general, families saw clients as children and also saw the residential care as replacements for them, couldn't see that we were trying to work alongside the clients.

41. Yes, I think they saw him like a great big 3 year old. I don't think they ever came to terms... and when his, you know, the way this person had come about and the way his learning disability had come about, it was talked about with real pain in their hearts.

42. Yeah, I'd say when I first started working, there were 2 female managers and they were both young and they just.. I'd never met..I was just 18, straight from college....and I had a certain group of friends and never really done much or seen much, and I met these 2 women and I thought 'wow, they're so intelligent and so beautiful and so compassionate' and you know they really, really....didn't drum it in to me but I just watched the way they worked with the clients and they showed me that, I mean I owe so much to them because the way I am now, they moulded me, moulded me into the way I am now.

43. I remember one time, he had a big mat in his bedroom and a beanbag and we both lay on the beanbag and he put his arm round me and we read a book and nodded off for a short period of time and it was so lovely and I thought 'he's getting so much pleasure out of me being here and I'm getting pleasure out of making him happy' and I thought, yeah, that was our special time together for the first time.

44. It's just like, yeah it would be great if we could just help people to be as normal as possible but it's not like normal is so special, is it? Normal is often greedy and horrid.

45. Often as not he would go to his room and just be really angry, shouting and everything and sometimes we knew what the reason was and other times it was very difficult to recognise what it was.

46. Some people I've helped haven't been... attractive or the way they verbalise or whatever makes it very difficult...immediately puts people off and it takes that extra effort to feel comfortable sitting with someone or whatever.

47. I think the first time he smiled at me was quite a major thing for me, because it just seemed to be a smile of recognition. Maybe I was reading that into it but it had never happened before and this was nearly a year. So that was quite a major thing and it really meant a lot to me.

48. I think sometimes I got so wrapped up in that, as you do, making sure he was physically well, rather than looking at him as a whole person.

49. I think you can only guess at how he's feeling from his behaviours, agitated or relaxed...anything else, feeling happy or sad, I wouldn't really know.

50. There is still an awful lot I don't know about him because it's all about my experiences with him, like I say, all about doing things but sort of spiritually, it's very

difficult to know how maybe he feels or what... I've no idea what his real feelings are toward particular people. It's frustrating not being able to know, you feel you're only scratching the surface really.

51. . I do find it very difficult, aspects of helping are very difficult because he was so vulnerable.

52. There were lots of things I hated. I hated being out in town and I used to get incredibly embarrassed by incidents, you know, in a supermarket or café, people doing the most outrageous things, it used to really crush me sometimes..... and it would make you really embarrassed and really angry at that person.

53. Yeah, sometimes it would be really nice for someone to say 'thank you' in whatever way someone could, even if not able to speak, get something. But I think if you're working with people that are very egotistical, very self centred, not generally the sort of people that in my own social life I would have anything to do with at all, but I find myself supporting people who are completely involved in their own lives.....

54. Yeah and that's difficult, because sometimes you're trying so hard to treat someone as you would anyone else but then you have to pull back because that person has a learning difficulty.

55... Well, I've had a few reactions being out and about with him. Once we were listening to some jazz in a park and the saxophonist passed some comment like 'it's really sad, isn't it or ' what a tragedy'

56. I think a lot of people still have very traditional views....I think it's still quite negative unfortunately or ...there are still people who don't have that much contact and I think people are still quite fearful of seeing people that are in wheelchairs and obviously have really profound learning disabilities.

57. *And how did those families view the clients?*

Well, sometimes it's difficult because they still can be quite...still treat them like children which is always difficult when you're trying to project that person as a young man or a young woman and they come in and really sort of play with them or whatever. It's hard.

58. He used to bring his hand up to his mouth and keep it there if he was enjoying himself. If he didn't like something he'd bite his hand.

59. . The other thing we used to do was go to gigs, concerts and it didn't seem to matter what sort of music it was, he absolutely loved it. I would take him to something I really didn't like but we had tickets and he would love it, the decibel level seemed to be what made him enjoy it—he'd really move quickly backwards and forwards and putting his head back and laughing, manic sort of laughter which I hadn't seen in him other than at gigs. Then on the way home he would get absolutely exhausted and just flop.

60. Yes because normalisation, it was the way. We believed it was the best way to be.

61. that was recognising that he was a human being first and someone with learning disabilities second.

62. , But then when you saw staff who blatantly treated people badly, poor care staff, it made you even more inclined to knock on the door and to say 'What would you like to wear today?' You know well enough that that isn't a choice for them but you know, as a principled person wanting to give good care, you want to do that.

63. I find the most difficult thing is other team members that are, in my opinion being purely selfish and carry out an activity for themselves, because they want to do that particular thing. When they don't put the client first that makes me annoyed.

64. I suppose I started thinking of him as..it sounds terrible, like I different think of him as a person before, but I started thinking of him as a personality because he was a young, lively individual who liked music and liked going out, liked a drink, liked the sweetness of a pineapple, seemed to like going to the pub but none of that had been done before.

65. No, it was people around him, like his mother used to say things about him and I'd think 'I don't think that's right'. She used to say he was sexually inactive, couldn't possibly have a sex drive, well that wasn't true because clearly when he used to lie on his mat, he used to roll over and he would be masturbating basically and his mother just wouldn't have it, 'not my boy'. But he's a man and her not recognising that, it's just crazy really and how we dealt with that was we'd let him have that private time

66. . It was only after 6 months that I really started to relax and be able to be myself in front of them. Before that I was 'oh my God, they're not like normal people'. And I don't think we can say they are exactly like everyone but no-one's the same.

67. Whereas the other chap I was talking about, the one who was lively, he used to grab people, little children, and that was scary for people and they would back off as soon as they saw him and staff would, with safety, try to encourage this person to be free, not to be sitting in a wheelchair because he could walk and we would try to encourage that. But the perception was one of fear.

68. *Did you get a sense of how these professionals saw the clients?*

Well, I never really saw them *with* any clients. They only talked about them . It was always talking between the social worker who never saw the client and the occupational therapist and the physiotherapist.

69. And the G.P's, I remember a situation in another group home, where the G.P wouldn't allow a female client to register with a female G.P. All the young people had to register with the same G.P because it was easier that way because he had all the people with disabilities, and the receptionist said this to me 'all the people with disabilities are with Dr. 'X'. I was furious. I was very young at the time and I thought 'this is wrong', seeing people just as a group.

70. The staff, how the staff treated the clients. There's a big difference, because if you did have people who didn't have any concept of treating people in the way that I and lots of other staff did, it made the shift difficult. If I wasn't working directly with a particular client and I saw they weren't being treated in the way I felt they should be treated, then it made my life difficult and I was thinking it must be making the client's life difficult, more inconsistent, than it needs to be. So the staff group were really important.

71. With clients, yeah. There was a woman who I worked with who was deaf, blind, epileptic, sort of was incredibly lively and sort of would not stop, she would be up all night when you did a sleep-in. And you just thought 'this woman would be a party animal', and I couldn't believe it half the time that she was considered to have a disability, because she was so perceptive and so clever.

72. Yeah, facial expressions. You can see annoyance and happiness.

73. He can show happiness, annoyance, dislike through vocal patterns.

74. and we don't really look into a person's disability, we don't really consider that as part of the question, they are the person we work with and that's it.

75. now I work with him as like a friend. I don't see him as anything else.

76. If you went shopping in Tesco's I think, well I know, and I've experienced it with people, that they find it embarrassing. I've seen people walk down an aisle and then turn around and walk down the other side before confronting the situation. At first when I started working here, it annoyed me but now I understand it's people's inability to come to terms with it. No fault of their own, they've just never experienced working with people.

77. One set of parents, they used to visit quite regularly. They come in and they see their child as a child and the way that they communicated with him was very much like a father/ son or mother/ son thing.

78. But I do think that sometimes you can't see the person underneath without the experience, and of course you can't do that necessarily, you know the work load a psychologist has, they just spend as much time as they need to.

79. I look at everybody the same, in fact some of the clients I work with are far more intelligent than I am.

80. I think sometimes I get annoyed when other members of staff don't really work here for the service users. They look at it as a money job. And because a lot of it is repetitive and it becomes annoying to them

81. ... but I think if you are constantly surrounded with children, for example, if you work in a nursery, a lot of your day to day thinking is on a child's mentality. Without wishing to compare children with adults with learning disabilities, I think it brings you to a level where you have to escape it sometimes, to be able to bring

yourself back to where you are. And I'm not saying we go lower or higher than other people but there is a level there that you need to get back to.

82. I think there is a level of understanding with clients with a learning disability that, it does stop, and I'm not being unkind, I think there is a mentality that does stop. It might continue in small, narrow fields but I think the development of their minds or their brains, it does stop.

83. and they are very much like they are family to me, in fact, in some respects closer than family, because you don't have that fighting that you have between families or all that self- opinionated, all those different opinions from people in families. It's very mutual, very laid back, very easy going.

84. , but that's the only sort of time you can sit with him and talk to him and get him through it, and after 5 or 10 minutes he's had enough. He gets agitated and starts shouting and biting and you try to move on to something else.

85. It's an elimination process really and of course, knowing the client. If it was a new member of staff, he'd sort of play the game, he knows that that person doesn't know him, you see

86. . I keywork him and I've had this conversation before in supervision and he is, we all agree, he is the most difficult person to work with because of his communication, because of his disability, you just don't know what's going on. It's very, very difficult at times.

87. But when people see people in wheelchairs, they don't see the person, they just see the wheelchair.

88. No, I don't know what's going on, and that's the most frustrating part about the job really. Because we've got people with all sorts of learning disabilities, some of them you know what's going on, you can actually verbally communicate or eye contact with some people and some people read lips and you can see what they want or they know what they want and you can tell this. But you don't know all the time, sometimes it's impossible and it's a process of elimination.

89. . I have been in hospital with 2 clients as a carer. One man had to have an operation. He was quite frustrated because there were things he wanted that the hospital weren't providing so he actually shouted a little bit and got things moving a bit quicker. And once they realised that this person was a person, and not just a person in a wheelchair, then the care was excellent. At first they just saw him as a disabled person, part of a number.

90. . at the hospital. I was talking to the nurse and she said 'it's been really nice having your team here because you know her needs and we don't and it's something we need to look into.' So some good came out of it. So we knew the clients needs and it made it a lot easier for the hospital, otherwise they would have had to have a person there 24 hours a day.

Appendix 9

Quote	Theme number (investigator)	Theme number (rater)	Quote	Theme no. (investi)	Theme no. (rater)
1	3	3	47	4	4
2	4	4	48	7	7
3	2	2	49	2	2
4	5	5	50	2	2
5	8	8	51	5	5
6	7	7	52	5	5
7	2	2	53	5	5
8	5	5	54	3	3
9	6	6	55	5	5
10	2	1	56	5	5
11	2	2	57	6	6
12	3	3	58	1	1
13	2	5	59	1	8
14	9	8	60	9	3
15	7	2	61	7	7
16	1	1	62	9	9
17	5	5	63	9	9
18	9	9	64	7	7
19	5	5	65	6	6
20	1	1	66	3	3
21	1	1	67	5	5
22	4	2	68	7	8
23	6	6	69	7	7
24	9	9	70	9	9
25	5	5	71	3	5
26	6	6	72	1	1
27	1	1	73	1	1
28	8	8	74	7	7
29	6	6	75	8	7
30	5	5	76	5	5
31	9	9	77	6	6
32	1	1	78	7	8
33	1	1	79	3	3
34	1	1	80	9	9
35	6	6	81	6	6
36	5	5	82	3	5
37	4	4	83	8	4
38	5	5	84	1	1
39	7	7	85	2	1
40	6	6	86	2	5
41	6	6	87	7	7
42	9	9	88	2	2
43	4	4	89	7	7
44	3	3	90	2	8
45	2	2			
46	5	5			

74 agreements

Cohen's Kappa Coefficient

(Proportion of times agreeing (74/90) 0.82
minus Proportion of agreements (1/9) 0.11
expected by chance) = 0.71

divided by
1 minus proportion agreeing by chance (1 - 0.11) 0.89

k = 0.80

Categories for written client descriptions

Likes/ dislikes

Abilities (can do or is able to)

The disability

Communication (how client communicates, comm. difficulties)

Personality traits (dispositions)

Emotions

Shared activities (between respondent and client)

Social role (family member, friend)

Physical appearance

Aspirations (wants to)

Activities (what client does).

Difficult behaviour (agitated, aggressive, self injurious)

Positive label (good person, good to be with, work with)

Negative label (Difficult person to be with, work with)

Respondent - Tracy.

1

2

3

X is a man of slight build with a profound learning disability. He has no speech

4

5

though can use his vocal cords to laugh, cry, scream. He communicates through

6

pointing or touching objects or bringing an object to you. He is very difficult to motivate into any community events or indoor activities and is withdrawn. At home

7

he spends most of the day and night in bed though gets up for tea and food. At the

8

9

day centre he will stay in a room with you though participates very little. He enjoys lying down and hiding under clothes and blankets. He doesn't enjoy noisy environments or touch unless on his own terms. His main reinforcers are food and tea

10

and appears to have little enjoyment through anything else. He has bipolar disorder

11

and behaviours that can lead to violence towards objects or other people (and himself).

Respondent 6- Shelley

1

This man is tall and gangly. When I knew him best, he was around 29/ 30 years old.

2

This person was one of either extremes-lively to the point of hyperactivity or lethargic bordering on comatose.

3

4

He seemed to have a great zest for life- Thoroughly enjoying the company of others
(when in the mood)- seemingly keen to encourage others (almost exclusively staff) to

5

join in his 'play'. This person really enjoyed physical 'rough and tumble'- He could

6

though become suddenly overwhelmed/ fed up and quite quickly show his feelings by

7

either screaming, or by becoming physically overpowering although these instances were few and far between.

8

This person had a great sense of humour and seemed to give long, lingering looks to staff/ family whom he felt pleased to see- if he wasn't interested he would slump

9

forward in his chair and clasp his hands together- putting his thumbs near to his eyes.

I always took this to mean 'push off' . He was able to move (although unsteadily).

11

And could grab things he wanted. This was encouraged in a controlled way by staff.

12

He was a physically demanding man but a fantastic guy to work with.

Respondent 9—Alf

1

2

3

X is a man with little verbal skills He can walk but communication is very

4

5

difficult. Because of his disability he becomes very vocal, agitated and frustrated.

6

7

Also he has extreme seizures. At times he just gets wound up to the point you don't

8

know what to do. I key work him and in my opinion, he is the most difficult client in
the day centre to work with, especially at lunch times.

Tracy's description

<u>Extract</u>	<u>Category</u>	<u>Category given by rater</u>
1	physical appearance	physical appearance
2	the disability	the disability
3	communication	communication
4	abilities	abilities
5	communication	communication
6	negative label	negative label
7	activities	activities
8	activities	activities
9	likes/ dislikes	likes/dislikes
10	disability	disability
11	difficult behaviour	difficult behaviour

Shelley's description

<u>Extract</u>	<u>Category</u>	<u>Category given by rater</u>
1	physical appearance	physical appearance
2	activity	difficult behaviour
3	personality trait	personal trait
4	likes/ dislikes	likes/ dislikes
5	likes/dislikes	likes/dislikes
6	emotions	difficult behaviour
7	difficult behaviour	difficult behaviour
8	personality trait	personality trait
9	communication	communication
10	abilities	abilities
11	abilities	abilities
12	positive label	positive label

Alf's description

<u>Extract</u>	<u>Category</u>	<u>Category given by rater</u>
1	communication	communication
2	abilities	abilities
3	communication	communication
4	disability	disability
5	emotions	emotions
6	disability	disability
7	difficult behaviour	difficult behaviour
8	negative label	negative label

Cohen's Kappa coefficient

Proportion of times agreeing (29/ 31) minus
Proportion agreements expected by chance (1/ 14

$$= 0.93 - 0.07$$

$$= 0.86$$

divided by 1 minus proportion expected by chance

$$= 0.86 / 0.93$$

$$\mathbf{k = 0.92}$$

Staff perceptions of adults with profound learning disabilities

Dear

I am writing with a brief summary of the results of the above research project, of which you were a participant. The results are presented in the form of the most important themes which I felt came out of the interviews. Obviously, the results are for the group of participants as a whole, and as everyone has different experiences and views, some of these themes may resonate with you more than others.

Throughout the interviews there seemed to be two important forces operating. Firstly, a change over time in perceptions of clients, from first encounter onwards. Secondly, there was a feeling of tension between various aspects of how clients are perceived. This will be illustrated further in the description of themes that follows.

1. Observation of clients

All participants described the use of observation of clients' facial expressions, noises, body language and other behaviour in order to gauge clients' needs, wants and feelings. This seems to be a necessary and constant aspect of the work and can be frustrating or upsetting as it is not always possible to 'decode' what the client wants.

2 Knowing versus uncertainty

Related to the above, this theme was about the importance of knowing clients, in order to understand them, but at the same time, always having to deal with uncertainty. Participants described getting to know clients over time and how this helped them understand clients. It was also important to have a sense of clients' history and background passed on. However, there were still times when participants felt they knew very little, even though they knew more than some others involved with the clients, such as outside professionals. Some participants also speculated about what was unknown, what the client might be thinking and feeling.

3. Client as normal versus different to normal

This theme was about participants sometimes seeing aspects of clients as 'normal people' (or occasionally better than normal people) and at other times being very aware of how different to normal clients are. This theme was also expressed by some participants as questioning what normality itself is.

4. Emotional connection versus detachment

This theme was about the importance of a sense of connection for how participants viewed the clients. There was a feeling of being closer to the client if there was a sense of reciprocity, recognition, acceptance, trust and sharing. The opposite of this was feeling that the client was in their own world, self centred and not aware of the participant.

5 Seeing client as a person versus not a person or part of the person

Some participants described not really seeing clients as individuals when they first began the work, or only seeing part of the person. Over time, this develops

into feeling they know the person more as a whole. There was also a perception that others less involved with the client, such as some outside professionals, don't see the whole person or only see clients 'as clients', not people.

6. Negative perceptions and feelings versus positive

Some participants described their own negative reactions and feelings regarding particular clients or the client group, either when they first began the work or before they were ever involved. This could be pity, fear, hopelessness, shock, embarrassment. Over time, as they get to know the clients 'as people' more positive feelings emerge. However, there are times in the day to day work when negative feelings can surface, and some respondents felt that negative events had temporarily 'damaged' their perceptions of some clients.

This theme also refers to the negative reactions of other people, particularly the general public. There was a mixture of feelings about their reactions and many participants had sympathy for the public, although still finding it difficult to deal with.

7. Locating self with clients versus power differences

This theme was about participants, as they got to know clients well, feeling they were 'with' the client. This could be as a friend, an advocate, or for some participants like family. The opposite to this was being aware of and uncomfortable with power differences between staff and clients, not being happy with being in control of vulnerable people.

8. Client as children versus clients as adults

This was mainly about the views of parents and families, who often see and treat the clients as children. This could conflict with staff trying to emphasise the adulthood of clients but there was also some sympathy for the views of families. Some participants also described sometimes seeing adult qualities, at other times childish qualities, in clients

9. Influence of colleagues, teams, care philosophies

This was about how participants' perceptions of the clients and the work was influenced by those around them. This could be in a positive way, with new staff being influenced by the attitudes of more established teams and by feeling part of a positive team. However, participants views were also shaped by seeing and rejecting bad practice in others. The influence of normalisation was also mentioned, although this was questioned by some participants in terms of not always being possible in reality.

Once again, thank you for your time and interest in taking part in this project. If you wish to discuss any of the above, please feel free to contact me,

Yours sincerely

Sarah Kenny